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The Impact of Care Act Easements

under the Coronavirus Act 2020 on older carers supporting family members living with dementia at home

Final Report / November 2022

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Context

In the extreme uncertainty and challenges faced during the first Covid wave in the United Kingdom, on 25 March 2020 Royal Assent was given to the Coronavirus Act 2020, giving emergency and enabling powers across a number of legal domains. Schedule 12 of that Act included the unprecedented power for local authorities in England temporarily to water down the majority of their key adult social care duties under the Care Act 2014 (referred to in this report as the "Care Act"). The relevant legislation and guidance is contained in **Appendix 1**. The steps were known as "easements" and came in four stages. Stages 1 and 2 made use of the existing flexibility of the legislation. Stage 3 permitted local authorities to cease formal Care Act assessments, applications of eligibility and reviews. Stage 4 permitted whole system prioritisation of need to avoid human rights violations. Easements were intended to be used in extreme circumstances for as short a time as possible, and to be regularly reviewed. Triggering stages 3 and/or 4 protected local authorities around England from legal action for failure to comply with their statutory duties if they were unable to do so because of crisis circumstances. The Care Act Easements: Guidance for Local Authorities (see Appendix 1) stated that the easements had been put in place to help the care system manage the pressures of the pandemic.

Eight out of 151 local authorities with adult social care responsibilities triggered stage 3 or stage 4 easements between April and June 2020. These were Birmingham, Coventry, Derbyshire, Middlesborough, Solihull, Staffordshire, Sunderland, and Warwickshire.

> **While eight may seem like a small number, many other authorities suspended or reduced services without triggering easements**

The easements however were short lived, one lasting just over a week and the longest, three months:

- Middlesbrough from 14 to 22 April 2020
- Sunderland from mid-April 2020 to 18 May 2020
- Birmingham from 14 April 2020 to 18 May 2020
- Staffordshire from 23 April 2020 to 26 May 2020
- Warwickshire from 9 April 2020 to 1 June 2020
- Coventry from 24 April 2020 to 2 June 2020
- Derbyshire (ultimately stage 4) from 31 March 2020 to 9 June 2020
- Solihull (ultimately stage 4) from 6 April 2020 to 6 July 2020

While eight may seem like a small number, many other authorities suspended or reduced services without triggering easements, potentially exposing themselves to legal action. However as will be shown in this report, the public mood was against easements. The eight local authorities that enacted easements came under considerable political pressures from lawyers, NGOs, and groups lobbying on behalf of care recipients and carers. Whilst this was not a definitive reason, it was a factor some local authorities considered when coming out of the easements. Although triggering easements remained part of the strategic planning of several authorities[1] the power to invoke easements expired on 16 July 2021, about one year after it had last been used. It was not renewed.

However, there was little or no understanding, then or now, of the consequences of Care Act easements for the people affected, nor what steps were being taken to mitigate urgent needs arising from reductions in support as a result of easements or pandemic conditions. The research team set out to investigate this issue from two perspectives: the point of view of social work and safeguarding leads who were making difficult decisions in crisis circumstances, and through the lens of family carers of people living with dementia at home. The focus of the in-depth qualitative study was on an especially hidden group of family carers: older people caring for a spouse living with dementia at home.

Older people caring for a family member living with dementia at home

Approximately 540,000 people with dementia live in the community.[3] Recent systematic and scoping reviews of the impact of Covid-19 on people living with dementia at home and their family carers show that they have faced, and continue to face, extreme challenges under Covid-19 including withdrawal of services, restrictions on movement, and high risks of illness and death.[4–7] For people living with dementia in the community, researchers have noted declines in cognitive functioning and physical health, worsened behavioural symptoms, increased levels of anxiety and depression, worsened social health, and difficulties accessing care.[5] Many living with dementia have not been able to retain information about what has been happening and have consequently become increasingly agitated or distressed.[5] Family carers have reported reduced access to health professionals and to vital care and support including day centres, support groups and respite care. Increases in caring responsibilities and carer burden with detrimental impacts on wellbeing, mental health and social health have all been documented.[4,8–10] Yet this group of carers is often invisible[11–17] and has received very little support in the pandemic.[4]

Among family carers, older spousal carers are a particularly significant group.[11] People over 70 were advised to remain at home, even if not clinically vulnerable, because of the exponential risk of dying from Covid with increasing age. Couples were likely both to be shielding or staying at home, and even when shielding was lifted, older people remained and remain at high risk of poor outcomes and death from the virus. Commonly, family carers in this age group themselves have challenges with activities of daily living, provide more intensive care for longer hours, and have lower quality of life than younger carers.[12] Furthermore, caring for a partner with dementia is recognised as one of the most challenging caring roles.[18] Often, these carers do not receive sufficient support because of assumptions that they are coping together; they feel ambivalent about requesting support, and report being anxious, socially isolated and lonely.[19] Such carers typically have their own high levels of health and care needs, but are invisible in research and policy.[11,13,20] This is an extremely important group therefore for us to understand the lived consequences of policy actions, and can act as a litmus test for other groups with high levels of social care need.

Older carers also play a vital role in supporting the health and care system, often caring for parents, partners and adult children living with multiple conditions and challenges. The role of older family carers in facilitating hospital discharge and relieving pressure on emergency admissions was never more apparent than in the pandemic, especially in the face of severe shortages of home care staff and unavailability of care home places.

The purpose of this research

The motivation for this research was therefore to find out about the consequences of triggering easements for people with high levels of need, how these interacted with the consequences of the pandemic, and whether there were material differences for carers in areas where easements were triggered compared to areas where they were not. The objective was to investigate the impacts of Care Act easements on older carers of people living with dementia at home to make recommendations about the operation of this legislation now and in the event of another wave or similar pandemic.

In particular, the project aimed to:

i. document the impacts of care easements and reinstatement of statutory duties;

ii. compare these with experiences in local authorities where easements were not formally triggered but services were cut;

iii. understand how policymakers with safeguarding responsibilities approached the issues;

iv. understand and document current urgent needs.

Methods

This research was conducted in collaboration with project partners, national charities TIDE and Making Space, who support thousands of carers of people with dementia, as well as an advisory board of five older, co-resident, spousal carers who worked closely with us throughout the project at all stages. The interview schema, survey instrument and outputs were co-produced with carer input from our advisory board and the assistance of our partners. Join Dementia Research and the NIHR Clinical Research Network led by the Manchester CRN provided considerable support for study recruitment as did many other organisations and agencies. These are listed with grateful thanks at Appendix 2.

The project took place in four workstreams, as follows:

- 48 in-depth interviews with people over 70 who had been supporting their spouse or partner living with dementia to live at home in England. Approximately one third of the interviewees were in easement local authorities and two thirds in non-easement local authorities.
- In-depth interviews with 27 Principal Social Workers/Safeguarding Leads (n=22) and/or others in leadership at 20 local authorities (n=5); five had invoked easements and fifteen had not.
- Drawing on the qualitative work, a survey of caregivers who were supporting a family member living with dementia at home from across the UK (n=604).
- Legal analysis of the operation of the Care Act easements in light of the empirical findings.

The two in-depth studies of carers and social work/safeguarding leads were undertaken concurrently between May 2021 and July 2022. Routes to recruitment are set out in Appendix 2. Interviews were semi-structured, undertaken via telephone or zoom, and between 30-90 minutes in duration. Transcription and analysis were undertaken iteratively so that findings emerged and fed into future interviews across both groups. This enabled triangulation of emerging data between professionals and carers in constant feedback loops. In both interview and survey arms of the study, the main focus was to interview and survey those people who were still supporting their spouse or other family member to live at home. Towards the end of the project, the team also interviewed four older people whose partners had died and five whose partners had moved to residential care, to better understand the experiences of people in these situations. A description of the characteristics of the sample of older spousal carers interviewed is contained in Appendix 3.

The qualitative data analysis took place via iterative line by line coding and constant comparison of data, incorporating a flexible deductive process of coding.[21,22] As well as adopting this iterative process, the analysis of the Principal Social Worker and Safeguarding Lead interviews drew on Spradley‘s Developmental Research Sequence method and relational theory of learning[23] considering how people acquire meaning through semantic relationships between actions and/or objects (see Appendix 4). Analysis began with codes drawn from the literature and prior understandings of the situation; these were not rigid and were viewed as starting guidelines. Codes were changed, eliminated, and supplemented with new codes during the process, ultimately organised into a conceptual map enabling presentation of findings robustly supported by evidence. Empirically, the focus of the analysis was on understanding respondents’ perceptions of (i) what has happened, (ii) how this has happened, (iii) why this has happened and (iv) carers’ immediate and pressing needs.

The analysis of qualitative interviews and deliberations with the project carer advisory board and partners shaped the subsequent survey, which was piloted and amended to make sure that the questions were salient and would inform the principal goals. As there is no national sampling frame for caregivers, and family members supporting people living at home with dementia are an especially hidden group, the survey is an observational non-probability non-randomised sample. The survey fieldwork took place between April and July 2022. Links to the online survey and paper copies were shared by organisations in groups, newsletters and by targeted mailings. In all, 622 people accessed the online survey of whom 543 proceeded past the participant information pages, and of those 451 met our primary criterion of currently supporting a family member living with dementia to live at home. We received 154 paper surveys back of whom 153 met this criterion. The data from online and paper surveys were merged into a single dataset of 604 respondents for analysis. The survey and technical details are included in Appendix 5.

Legal analysis and research into the operation of the easements continued throughout the project in the light of emerging empirical findings.

The research was approved by the NHS HRA Social Care Research Ethics Committee, IRAS 293584, REC reference: 21/IEC08/0001.

Findings

This research has revealed a complex picture of local authorities acting under extreme pressures with greatly stretched resources in crisis circumstances, and of carers struggling without access to many pre-existing support routes while those they cared for were rapidly deteriorating mentally, physically and socially. The impact on carer health and wellbeing has been profound.

Summary of key findings

The findings can be summarised as follows:

- In the crisis circumstances of the pandemic, Schedule 12 of the Coronavirus Act enabled local authorities to invoke "easements" which temporarily suspended their statutory duties under the Care Act 2014. Eight out of 151 local authorities made use of this legislation, for short periods ranging from one week to three months.
- Across both local authorities in this study that invoked easements and those that did not, evidence from carers and local authority social work leads revealed that carers and the family members they were supporting experienced significant changes from their usual care and support, which in many cases resulted in lower wellbeing and unmet need. The survey results suggest a population in acute distress and suffering from very poor mental health.
- Given the evidence of reductions in support to carers at a time when their needs were increasing, and the apparent extent of unmet need among carers in this study, on the face of it there appears to have been a high risk of instances where statutory duties under the Care Act towards carers were not met – including for assessment, provision, communication, and reviews. If this is the case for any individual in any given local authority, Care Act easements were likely to have been required at that time.
- Although the experiences were similar across the local authority areas in this study, easements were differentially implemented, soon revoked, and not in force for any local authority beyond July 2020. There appears to have been little consequence – whether political, legal, or regulatory – for local authorities that did not invoke easements. However, for the local authorities that did, there was considerable pressure from lawyers, NGOs, lobby groups and adverse media attention.
- The pandemic conditions therefore appear to have set a precedent whereby diminished provision under the Care Act has been provided to caregivers and the people they support, below the levels previously thought to be the minimum acceptable, without litigation or regulatory intervention or consequence. This was due to stretched resources and the complex conditions that prevailed, but if it is correct that this could have been done lawfully without Care Act easements, there is a danger that Care Act statutory duties may have been permanently undermined.
- This is because local authority resources for social care, especially staffing levels, are reported as increasingly critical, and some suggest they are in a worse position than in the first year of the pandemic. If the pandemic conditions justified unmet social care need without needing to ease Care Act duties, it is unclear what state those duties are in now. Not recognising the strength of statutory duty in pandemic conditions runs the risk of their *de facto* dilution to mere powers in the circumstances now prevailing in many areas. There are critical stresses in carer support and provision.
- Carers seem unprotected with few options. They are dealing with an unclear legal situation and widespread stress and burden.

Each of these points will be expanded below.

Analysis

Throughout this report we use the word 'enact' when referring to easements, as this is the language used to describe the process of invoking easements by nearly all Principal Social Workers and Safeguarding Leads interviewed. The definition of the word 'enact' is to 'make law' or to 'put something into practice' and whilst local authorities were not making law in the legal sense of the word, this may reflect the Principal Social Workers/ Safeguarding Leads seeing the easements as effectively changing the law and/or putting it into practice.

The operation of the Care Act and easements

The Care Act shifted the focus of local authority statutory duties away from the provision of services towards a duty to meet individual needs, which, if left unmet, would significantly impact a person's wellbeing. Duties to assess needs, offer services to meet eligible needs, financially assess, and prepare and review care and/or support plans are set out in the legislation and accompanying Regulations. Section 78 of the Care Act also requires local authorities to act under Statutory Guidance, from which they can depart if there is a 'cogent reason' for doing so. It is perhaps trite to say that the unprecedented circumstances of the Covid-19 pandemic were likely to have provided *prima facie* 'cogent reasons' for departure from guidance where necessary. 'Cogent reasons' however, cannot be used in a blanket sense to change provision across a local authority; they are specific to individual circumstances, and when considering whether to depart from statutory guidance their use must be approached on a case-by-case basis.[24–27] Importantly, local authorities were not permitted to depart from their statutory duties, even in unprecedented circumstances, unless or until easement stage 3 was triggered. If they did so without the protection of easements, they were liable to censure and litigation. The difference between statutory duty and guidance thus became a central legal question in the pandemic.

Statutory duties include the following. Local authorities are duty-bound to assess those who "appear" to need care and support (s.9), as well as their carers (s.10). They must determine whether the person is in fact in need of care and/or support, what those needs are (for both), how those needs impact on their well-being, the outcomes they wish to achieve, and whether – and to what extent – providing care and support can help achieve those desired outcomes. They must then determine which assessed needs are eligible for local authority support (s.13), assess financial resources (s.17), meet eligible needs (ss.18-20), prepare and keep under review care and/or support plans to meet these needs (ss.24, 25, 27); and give written records of assessments (s.12). Section 30 and accompanying regulations also require local authorities, if certain conditions are met, to provide or arrange the provision of preferred accommodation.

The Coronavirus Act 2020 envisaged that there could be circumstances under the pandemic in which local authorities simply could not meet their statutory duties and legislated a mechanism for what could happen in those circumstances. This required formal invocation of "easements" of the Care Act under Schedule 12. If stage 3 easements were triggered, local authorities would not be required to do any of the above, and at stage 4 could prioritise people's needs, with a duty only to meet needs where failure to do so would breach a person's human rights. Prioritising one person's need to be fed over another's need to avoid social isolation, for example, required heightened scrutiny with fortnightly reviews and Department of Health and Social Care oversight in stage 4 easements areas.

It is important to document what happened to carers, and the family members they care for, to understand whether the needs of those requiring care or their family carers were met in the early pandemic conditions.

Significant changes from usual care and support, resulting in lower wellbeing and unmet need

Carers and the family members they care for experienced significant changes from their usual care and support, resulting in lower wellbeing and unmet need. This was the case across easement and non-easement areas, with no discernible differences.

Data in the section which follows is drawn from 48 in-depth interviews with carers over 70 caring for spouses or partners living with dementia at home and a survey of 604 carers supporting a family member with dementia to live at home. Interviewees were aged between 70 and 86 (mean age 76), supporting a partner or spouse living with dementia aged between 62 and 90 (mean age 78). A description of the characteristics of the carers interviewed is included at Appendix 3. In the survey of family carers, the mean age for people supporting a spouse or partner living with dementia to live at home was 73 (with many over 80) compared with those supporting a parent (mean age 54). Three quarters of those supporting parents to live at home did not live with them, whereas spouses were almost all co-resident. Descriptive statistics from the survey are included at Appendix 6.

Carers and those they care for experienced multiple changes for the worse to the care and support they received

The data revealed widespread reductions in residential respite and home care provision (albeit the latter was commonly at the request of carers), suspension of day centres and day services, closure of support facilities and suspension of befriending and in-home sitting services. Aside from the pandemic, the progressive nature of dementia is such that it would be expected that the needs of people living with dementia and their carers would have become commensurately greater with time, with people living with ever higher levels of need as the pandemic unfolded. Moreover, in line with other research evidence[3] and reports from the local authority leads interviewed, carers in the interviews and survey consistently reported a strong belief that there had been an acceleration in the cognitive decline and physical deterioration of their family members living with dementia at home during the pandemic. This suggests that in addition to the needs of people living with dementia at home not being well met, there was on the face of it also an accelerated increase in carer needs for support and respite.

Principal Social Workers/Safeguarding Leads and carers alike also reported high levels of isolation and loneliness for older carers, difficulties in accessing support, and declines in caregiver mental and physical health. For some carers, there were problems with enlisting any help or assessment from local authorities, especially for self-funders, and in navigating the minefield of support and care provision. The data from this study did not reveal any difference in the ways that family carers supporting people with dementia living at home experienced the pandemic across easement and non-easement areas, but across both, the impacts of the reductions in local authority, community, third sector, and private support and services on the carers in this study were profound. The pandemic exposed existing fractures in the care of older people at home, exacerbated these, and added new ones.

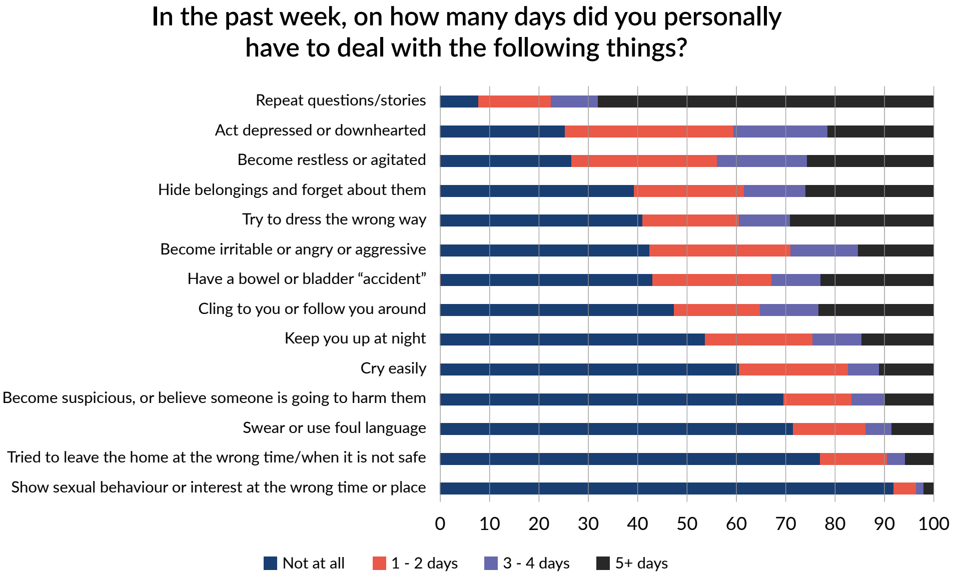
As shown in Table 1 the survey data revealed for 30% of respondents someone had to be with their family member for 24 hours a day and they could not be left alone at all, and a further 23% could only leave for short periods such as less than an hour. Figure 1 shows that many carers responding to the survey were having to cope with multiple behaviours that could be stressful, exhausting and relentless for a caregiver, for many every day. These included: forgetfulness; depression; restlessness and agitation; hiding belongings and forgetting about them; difficulties dressing; irritability, anger and aggression; incontinence (bladder and bowel); clinging behaviour; disrupted sleep; crying; becoming suspicious and believing someone was going to harm them; swearing or using foul language; trying to leave home when it was not safe; and showing sexual behaviour or interest at the wrong time or place. Other problems reported included difficulties eating; difficulties communicating and incoherence; hallucinations; screaming, biting, and throwing furniture; confusion, anxiety and disorientation; inability to use appliances; immobility including being confined to bed; and apathy. Eighty-one per cent of carers in the survey were managing and coping with one or more of these issues on 5+ days in the week, and 33% of carers were managing five or more complicated different behaviours each week. Twenty percent of respondents were dealing with bowel or bladder ‘accidents’ every day and almost a third on at least 3 days in the week. A small but still substantial percentage of respondents – 17% were dealing with ten or more issues from this list each week. It is easy to see how this could become overwhelming.

Table 1*: Does your family member need someone to be with them?*

Does your family member need someone to be with them? Please select whichever answer most closely fits your situation:	Percent
Yes, 24 hours a day	30
Most of the time, although they can be left for short periods e.g. less than an hour	23
Much of the time but they can be left alone for a few or several hours	17
They can be left alone for stretches of time but need oversight/help several times a day	13
They can be left alone for stretches of time but need oversight/help once or twice a day	10
They only need someone with them during the night	0
No, they do not need someone with them	6
Total	100
	n= 524

Source: Carer Survey

Figure 1: *Behaviours in the last week*



Source: Carer Survey, n=506

Sixty percent of survey respondents reported that either they, the person they cared for, or both of them were advised that they were vulnerable and at risk of severe illness if they caught Covid-19 and should stay at home at all times and avoid any face-to-face contact (advised to shield); 95 per cent said that their family member was mostly self-isolating/staying at home throughout the pandemic and 84 per cent that they themselves were mostly self-isolating or mostly staying at home throughout the pandemic. What happened to carers, happened behind the closed doors of the household.

> **Across both easement and non-easement areas, the impacts of the reductions in local authority, community, third sector, and private support and services on the carers in this study were profound**

Home care

None of the interviewees and few survey respondents reported that the local authority had initiated a reduction in the frequency or duration of home care visits available to their partner following the start of the pandemic in March 2020. However, several carers reported having made their own decision to temporarily suspend, delay, or terminate support from home care (and in-home and befriending services) during this period, which left them struggling without necessary support. The risks regarding transmission of Covid from home care workers was regarded as just too great. However, in some instances their partner's care and support needs were such that they could not do this. Several carers acknowledged the risk that home care presented to themselves and their partners but felt that reducing or suspending home care visits was untenable due to the level of their partner's needs. For many in this situation, inconsistency and unreliability of home care workers, lack of PPE, problems in choice and timing, high turnover of staff, and unvaccinated staff were matters of real concern, as typically expressed here:

> *We are having care all the time and with different care agencies. But my concern was how much hygienic things they were maintaining right in the beginning, was not very much. I had to always complain, yeah, because then pandemic did not become such a scary at that time. They were just coming without gloves, without this. And always a constant struggle. (Interview 15: male carer, aged 80, easement area)*

Voicing concerns regarding aspects of care provision that were believed to be of poor-quality, whilst also feeling reliant upon the continuation of the service to support their partner to continue to live at home, was described as risk-laden and steeped in apprehension regarding the potential loss or withdrawal of care, as described in the following examples:

> *I would always ask, "Have you had your vaccines?" Because at that point having the two vaccines was supposed to help protect yourself and others. But one of them was one of these disbelievers. Called the government fascists and hadn't had any vaccines, didn't believe in them. Didn't think there was a pandemic, but the care company was still using him. And whilst I might have been able to ring the company and say, don't send him. I just felt I couldn't, you know, that I needed the support. (Interview 40: female carer, aged 73, easement area)*

> *[The] shortage of carers has affected us. We have to be grateful to have anyone, standards have gone down but we have to keep quiet. Don't rock the boat S.W [Social Worker] said. (Survey respondent)*

Despite very high levels of need, four interviewees described having decided to disengage with home care services entirely after having initially tried to persevere with the service, due to feeling that the stress and burden created by the high turnover of carers, lack of choice and personalisation regarding timing of visits, and unreliability of the service, outweighed the benefits of outside assistance. These families then endured an especially high care deficit.

The legal implications for local authority statutory duties when care recipients decline high-risk or low-quality care in the home that they did not consider met their needs, or indeed decline respite care discussed below (see page 15) that was perceived as presenting greater risks than staying at home, was not an issue litigated in the pandemic. However even in these circumstances the statutory duty to assess needs remained clear. We refer to this issue of apparent need and assessment further below (see page 29).

The mixed economy landscape of home care commissioning and provision posed further challenges to carers that felt the need to raise concerns. One carer described the difficulties that they had experienced following the sudden cessation of support from one home care agency following the local authorities commissioning of an additional agency to provide night-time cover because '*they virtually refused to speak to me because I think they look on the – their client isn't me; their client is the Social Services' (Interview 37: male carer, aged 76, non-easement area).* Another who was self-funding a substantial package of home care, described feeling largely unsupported by the local authority in terms of raising and pursuing concerns regarding the quality of the care being provided by the care agency. The carers that described feeling the most satisfied with the home care that their partner had received during the pandemic had typically arranged home care privately, via local care agencies, which was associated with greater consistency regarding allocated home carer workers.

Day centres, day care, support groups and day activities

All the interviewees whose partners had been accessing a day centre or day care prior to the pandemic reported that this provision had been suspended for various periods of time following the start of the pandemic. This left significant unmet need resulting in stress and anxiety. Many of the carers whose partner's accessed day care emphasised the importance and value of day care in respect of being able to access a regular break, as exemplified here:

> *She went to a day centre, you know, for five hours. And that was just like a release valve to me, you know. Just getting five hours was like two weeks. It was – just as soon as I'd drop her off, it was a weight off your shoulders. For all you knew you had to go back for five – you know, in five hours' time, but it was just something that you really looked forward to, you know. (Interview 39, male carer, aged 76, easement area)*

Carers' experience of diminished day centre services was almost universally negative and the lack of respite that the day centres had previously provided was and remained a very serious problem. Carers emphasised the crucial value of day services in terms of enabling a break from their caring responsibilities, whilst also providing opportunity to attend medical appointments, undertake practical activities like food shopping etc, and spend time with wider family and friends. All of this was lost, and the pressures on carers were extreme. Some carers who had not been in receipt of sitting services or day care prior to the pandemic described difficulty or waiting lists when trying to gain access to this support at later stages of the pandemic:

> *I did try and talk to [healthcare trust] or whatever they call themselves. And say, what's the possibility of getting a carer in, once a week or something? No, sorry we – I think their words were, 'we've had to discontinue all those facilities since Covid and that also applies to day centres as well where you could take [partner]' (Interview 41: male carer, aged 77, easement area)*

> **Lack of respite that the day centres had previously provided was and remained a very serious problem**

The majority of carers indicated that their partners had not been offered any alternatives to day care when these services closed, although some reported that the centres had provided an online group or session, or sent activity packs in the post. Whilst these alternatives were welcomed and appreciated by carers, many carers reported that their partners living with dementia struggled to engage with online sessions offered. These alternatives did not meet the needs that were being met by attendance at the centre, typically socialising and activities for the person living with dementia, and the opportunity to have a break from caring for carers themselves. As one of the interview respondents put it:

> *Of course, he didn't see the people he was used to seeing. It impacted on me because I had him twenty-four, seven. And I know it sounds awful but when you live with it twenty-four, seven it drives you potty. (Interview 29: female carer, aged 75, non-easement area)*

Similarly, support groups for both carers and their partners, including dementia cafes, memory groups, singing groups, carers groups, and lunch clubs, were reported to have closed at the start of the pandemic for varying time periods, with many having not reopened or been re-established at the time of the interviews, some of which took place two years after the start of the pandemic. Many carers described these groups as having been a vital source of support, social contact, advice, and information. For carers that felt confident using online platforms, the opportunity to continue to meet virtually was felt to be beneficial in terms of reducing feelings of isolation, however not all carers felt able or wished to join online groups, a typical comment here:

> *I downloaded Zoom because there's a Carer's Café as they call it, and you can go on it so many afternoons a week, and talk to other carers that's on it, and I tried me best to do that, and I couldn't get the link properly, so I came out of it. It isn't the thing for me. (Interview 17, female carer, aged 75, non-easement area)*

Moreover, many carers felt that their partners gained much less benefit from online alternatives to in-person groups due to difficulties communicating and interacting with the facilitators and other participants. Several carers noted that they were required to support their partner to set-up and engage with online groups which added to a sense of carer burden rather than offering a break or period of respite, as exemplified here:

> *I need to set up all the online for him. He does still use an iPad, he blows the screen up to maximum, he still will use an iPad, but he wouldn't be confident enough to locate a Zoom call for example…But he gets quite tired quite quickly with Zoom. If he's in a room and other people are there, and they have a cup of coffee in the middle of it, and somebody's laughing and talking, he would be far more responsive for longer. He can't do the same as me and you don't get the same interaction, and they still have to sort of – you know, when each person speaks and the face comes up with Zoom, he finds that disconcerting. So there are real disadvantages for him" (Interview 27, female carer, aged 70, non-easement area)*

Out of one hundred survey respondents who had been offered an online alternative to formerly face to face provision, 81 per cent reported that the experience was worse for one or other or both themselves and the person they cared for, with more than half (52 per cent) saying it was worse for both.

Residential respite

Care home respite presented complex problems with difficulties accessing this even in extreme need, and it being fraught with risks and dangers including increased risks of death from Covid, lack of visiting, stress related to lack of control and being able to check on family members, and the risks of rapid deterioration and a temporary move becoming permanent. Carers reported that availability of residential respite stays were initially reduced following the start of the pandemic, although several interviewees had requested and utilised periods of respite at points of crisis during the eighteen months that followed.

Several carers were concerned regarding the prevalence and risk of Covid within residential and nursing homes and had subsequently decided to forgo periods of respite that they had been assessed as eligible for. Restrictions on visiting were also a significant source of concern, as was the impact of any periods of isolation, and the potential for their partner to deteriorate and then subsequently be unable to return home, as explained here:

> *I think because friends – where he went for respite, I think they lost about twelve residents. And two of our friends, their husbands went in for respite and unfortunately it was when everything went into lockdown, and they've never come out. So, the home said, you know, they are still alive but the home said well, really they've deteriorated, because they couldn't see family or anything. And, you know, they just weren't fit to go home. So, I'm not prepared to let that happen to [partner] (Interview 3: female carer, aged 73, easement area)*

For carers that reached a crisis point, respite care was typically described as necessary and ultimately beneficial, however the restrictions on visiting influenced the degree to which carers felt at ease with the care arrangements:

> *So, a mix, really. It wasn't, you know, A1 because I was thinking, from [partner's] sort of perspective, that she's in a different environment. Are they looking after her? I can't access her. I can't check, and so on. So, you know, there was anxiety there. It wasn't a sort of total two-week rest, as indeed it should have been, but at least it gave me an opportunity to get things that I'd not been able to. You know, so quite mixed again. (Interview 19: male carer, aged 71, non-easement area)*

Carers' experiences of organising and arranging residential respite varied significantly, as did their perceptions of the quality of the respite care. Several carers, typically those self-funding the respite, described making arrangements directly with care homes, often without issue. However other interviewees described significant difficulty in terms of accessing or arranging the respite stays. One carer noted the challenges she had experienced in terms of trying to ensure her husband would have access to residential respite care whilst she was admitted to hospital for planned surgery; and several described being unable to book respite more than a week in advance of the stay and indicated that the process of identifying a respite vacancy took substantial time and resources, and caused a great deal of additional stress:

> *oh, that was the other thing I was offered respite care, twenty-eight days a year which I had to organise myself ...[]...I did use it, you know, but it's hard knowing what place to put him in. I had a list of about twelve care homes. Well he needed a nursing home because by the August he was classed as needing nursing care. It didn't work, not having people that understood diabetes. You know, he wasn't eating and they were still giving him insulin so his blood sugar was dropping to the point where he was collapsing... []... But I did, I rang round a lot of these nursing homes. And most of them, because I thought I might try and go away for a couple of days, I was only going to put him in for three nights the first time. Most of them said, "Oh, you'll have to ring up, you know, the week before," or, "We can't cater for his needs." (Interview 40: female carer, aged 73, easement area)*

As one survey respondent put it: *"[The] bidding process for respite care is brutal."*

Carers whose partners had experienced residential respite that was felt to have been of poor quality were often reticent to use respite again, despite having been assessed as eligible for further stays.

Access to services, assessments & reviews, and follow-up

All interviewees described a similar pathway to their partner's diagnosis: following consultation with their General Practitioner (GP) a referral was made to the local memory clinic; the memory clinic undertook an assessment and formulated a diagnosis. However, carers described varying levels of available support and follow-up once the diagnosis had been made. Many carers recalled that their partners had been discharged back to the care of their GP soon after diagnosis. Some carers, particularly those whose partners had been diagnosed with Alzheimer's, described a period of regular reviews by the memory clinic whilst medications, such as donepezil, were introduced and monitored, before being discharged back to the care of their GP. Some carers described their partner's discharge from the memory clinic as a cliff edge after which they felt they had no ongoing access to further support. This wider systemic issue became especially problematic during the pandemic. This description of being left on your own: "door slammed", "nothing coming to you", "abandoned", "left on my own", "nobody you could ring", "completely off the radar", was ubiquitous:

> *That, you know, this is it, you're just referred back to your GP. And so that's it, you know, you go away. You've got dementia, go and get on with it. (Interview 25: female carer, aged 82, easement area)*

Carers then described mixed experiences of accessing ongoing support from their own and their partner's GP following discharge from memory services. Some felt that GPs were not well situated to provide follow-up support, and some (see below) had found accessing GPs to be particularly difficult during the pandemic. But also, many carers highlighted their concern regarding the lack of ongoing medical review following diagnosis and described anxiety and uncertainty regarding symptom and stage progression. This was often associated with concern regarding preparing and planning for the future and a need for reassurance that they were providing the right level of support to their partners, that they had the right information for the stage that their partner's dementia had reached, and comfort that all options for treatment and symptom management had been fully explored:

> *But he's never been reassessed by any doctor, or anything in that time, so I have no idea how quickly this is progressing, and I just feel that it's wrong, I just feel that people with Alzheimer's they're given the diagnosis and that's it. You know, we know there's no cure, but I still think that they deserve some support… I mean I know there are different stages, and I haven't got a clue at what stage we're actually at, and I feel that a consultant should be able to tell you that, and that option should be there. (Interview 42: female carer, aged 72, non-easement area)*

Most carers described having received vast amounts of written information, contact numbers, links to websites, and signposting to community resources at the point of diagnosis. For some carers this was welcomed and useful, particularly those that described themselves as proactive and keen to engage in community groups and activities. However, many described the volume of information as overwhelming and untailored to their individual situation, and therefore difficult to engage with and utilise:

> *I know that, at the start, when we saw the consultant at the memory clinic, um, there and from the Alzheimer's Society also, we were presented with reams and reams of information and contacts and far more stuff than we could absorb at the time. And it might have been better in the whole system, as I say, regardless of Covid, if that came through a bit more as and when we needed it. (Interview 28: male carer, aged 74, non-easement area)*

The experience of trying to navigate fragmented information, services, and systems was also raised by several carers, as well as the amount of time and energy that navigating information and seeking support involved, which was difficult to do in addition to the care that they were providing to their partner:

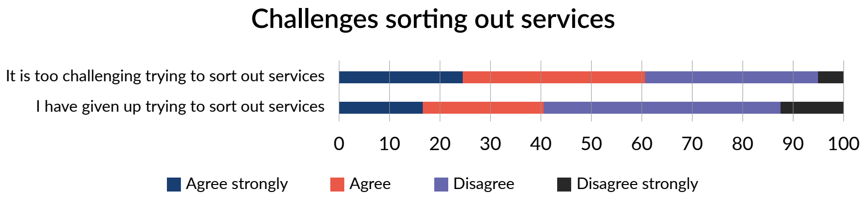
> *I think you've got to find it and I think when you're in the caring role, anything extra to that caring role, you've got to fight for. It's just – I mean, some days you can't even be bothered to open the mail because it's just another chore. You know, so if you've got the worry of having to go out and find care, it's a nightmare. It's just over stress. I think that's probably why – it's such a mine field (Interview 1: female carer, aged 72, easement area)*

> *Dealing with social services is more exhausting and problematic than caring. It is easier to take everything on my shoulder than ask more help. (survey respondent)*

Figure 2 shows that 41% of survey respondents reported that they agreed strongly or agreed with the statement that they had given up trying to sort out services, and just over 60% that it is too challenging trying to sort out services.

Some carers described their partner's discharge from the memory clinic as a cliff edge after which they felt they had no ongoing access to further support

Figure 2: *Challenges sorting out services*



Source: Carer Survey, n=490 & n=482

Current NICE Guidance[28] suggests a pathway with regular and consistent medical review and connection to social services via a named health or social care professional, but the data from this study suggest that this does not work consistently in practice, or for many, at all.[29,30] The carers taking part in the study reported no clear pathway to receiving timely information that relates to the particular stage of the disease and associated need for care, nor towards integrating with local authorities and service providers as needs progress. This became a major problem in the pandemic. At the time of first diagnosis, symptoms might be mild and care needs might not be significant. At that stage there is plausibly no need for the GP or other medical professionals to make a referral to the local authority and the information deluge may be largely irrelevant. The disease and care needs are progressive, sometimes changing only at slow pace. Without ongoing assessment, support and monitoring, changes in the illness, in the care needs, and in carer needs, are not visible outside of the household. It is likely this situation that leads to this largely being a 'hidden carer' group, as detailed below (see page 30), often only coming to the attention of services at times of crisis, with seemingly little opportunity for preventative intervention to support carers. In the survey, 34% of respondents said that their family member's needs for care had *never* been formally assessed by the local authority, and 57% said their own needs as carers had *never* been assessed. Respondents were also asked whether "Since the pandemic began in March 2020, has your family member with dementia had a medical assessment from the GP, hospital or community medical team assessing the progress of their dementia and their needs?". In the two years since the pandemic, only 52% of respondents said yes, with 44% saying they had not (and 5% unsure) (n=527).

The shift away from face-to-face and towards online or telephone appointments for GP and health related appointments was largely evaluated unfavourably by carers interviewed. Some carers described concern that remote consultations may have meant that signs of deterioration or ill-health were missed. Several carers voiced similar frustrations regarding telephone appointments regarding their own health needs. However, some carers felt that the availability of telephone consultations had expedited appointments for the person they cared for and were advantageous in terms of being easier to access than attending in-person clinics with their family member.

In the survey, 78% of respondents reported that they had wanted to speak to a GP during the pandemic. Of these, only 67% reported being able to do so, with 26% saying they had tried and been unable to reach a GP, and 7% saying that despite wanting to they had not attempted to contact their GP. About half of survey respondents reported having tried to contact health professionals or organisations apart from their GP seeking help, mostly the local authority, social workers, dementia or Admiral nurses, carer groups or carer support charities. Of these, 64% said that they felt they had received the help that they needed, with 36% feeling they had not. Survey respondents were also asked whether, since the beginning of the pandemic (2+ years ago), anyone from a service, agency or the local authority had contacted them to find out how they are managing: 34% said yes, but 66% said no. Of those who said yes, 22% reported that this was at least once a month, with 67% saying less than that but at least once a year, and 11% just once, more than a year ago and never since. Most (64%) found this contact helpful, but 36% said it was not, or they were not sure. Taken together, only a tiny proportion of survey respondents – less than 1% – were contacted at least once a month by someone from a service, agency, or the local authority to find out how they were managing. This is in the context (see Table 3 on page 24) of 52% of survey respondents having been in receipt of some form of formal help or support with their care of their family member living with dementia before the pandemic began.

This survey evidence tallies well with the evidence from carer interviews. Only a third of our interviewees recalled having received any kind of pre-emptive contact or phone call from their local authority, GP, or any other organisation such as carers hubs and associations, national charities, day centres and community groups during the pandemic. Those carers that did receive phone calls tended to describe them positively, particularly when that contact was from a known person or organisation, as exemplified here:

> *[Carers centre] were ringing – there was somebody from them ringing every month as well, or every fortnight I think to see how I was getting on and how we were. And that was quite a lifeline actually, you know, having people ring you. (Interview 40: female carer, aged 73, easement area)*

A few carers reported having received checking-in phone calls from their local authority, either from dementia teams/services or in connection to offers of support with shopping and prescriptions whilst shielding. One carer described the phone call and subsequent support as invaluable:

> *The council just rang me out of the blue. Because I was starting to panic, you know, when everything was closing down, and you had to order your food online. I didn't know what to do. But I did get a phone call from the council, and it was just out of the blue, and they said, "Don't worry about it. We will do your shopping. You just make a list and you tell them over the phone what you want." And it was a girl from the council that would do all the shopping, and she would say what supermarket I wanted to go to. So, I had a choice of Asda, Tesco and Sainsbury's, I think it was. Honestly, they were incredible. (Interview 30: female carer, aged 80, non-easement area)*

However, few carers interviewed received such calls. For some carers, not receiving any offers of assistance or queries as to how they were managing was associated with a sense of isolation and managing (or struggling to cope) alone:

> *So, as far as – from what I recollect from Social Services and things like that – we've nothing – I mean, same as you say, when the pandemic kicked in and everybody was locked down and that sort of thing, it was like isolation plus isolation. Because we didn't see anybody, but, then again, nobody rang, either, you know. (Interview 7: male carer, aged 77, non-easement)*

Carers assessments and assessments concerning the needs of the person living with dementia typically only took place following a request by the carer for a new or expanded package of care (as opposed to a planned review), or as often happened, following a point of crisis, such as an admission to hospital. Carers had varied experiences of reaching out to the local authority for assistance, with some feeling that the shift to telephone-only access had increased the difficulties they had experienced in taking this first step:

> *That was the first time I'd been in touch. And that – quite honestly, that is a nightmare because you just do not know where to start with Social Services. You've got a telephone number, because with lockdown half the staff's off on being isolated and you just, you know, the phone call was a major operation. You're just getting through to anybody (Interview 37: male carer, aged 76, non-easement area)*

There were complex interactions especially with self-funders. Carers across several local authority areas described having contacted their local authority for assistance as stresses mounted during the pandemic but were advised that they were only eligible to receive very limited information due to their financial status, without being offered an assessment or review of their or their partner's needs. These findings were mirrored by survey respondents. Our data reveal this happened both before and during the pandemic, in both easement and non-easement areas, exemplified here by this carer relating his experience:

> *Down the road I thought, right, we need care, something – you know. So rang [social services] up and I spoke to this guy. And I said, oh, I'm looking for home care, my wife's Alzheimer's. And, you know, it's getting a bit full on and I need a – I'm looking at a bit of help, you know, and this, that and the other. First question, he said, have you got – has your wife got more than £23,250? I said, "Well, yeah, don't worry." He says, "Oh, well, there's nothing we can do. I'll tell you what, I'll send you a brochure." I said, "Well, is there anybody you could recommend, you know, surely people who work for Social Services, you know?" "No, we're not allowed to recommend anybody or anything like that. I'll send you a brochure, you can have a look through that. Do what you want". (Interview 7: male carer, aged 77, non-easement area)*

While these systemic problems were widespread and a frequent narrative within our interviews, this experience was not universal, with some carers living in different localities reporting having been offered ongoing support from Admiral nursing services ("invaluable") or having been offered 'carers courses' of various formats. Carers' hubs and groups were frequently described as "a life saver", "providing practical help with compassion", and for some, it was carers hubs or organisations, for example who had arranged valuable telephone befriending services during the pandemic. Some carers also noted that their partners had still been able to access post-diagnosis support or education groups via the memory clinic or had been referred to NHS provided cognitive stimulation therapy courses.

Inequalities in accessing help and services

Overwhelmingly, in both interviews and the survey, carers reported negative, stressful, isolating experiences that had impacted adversely on themselves and the people they were supporting, leaving them at breaking point, or, for some, beyond. The data showed that some people could navigate the difficulties they experienced and the care deficits they were coping with better than others. Some carers had secured positive help, including eligibility for respite, signposting to additional services, or access to funds to cover activities for themselves. Many of the interviewees spoke at length about the crucial support that they received from their children, wider family, friends, and neighbours throughout the pandemic, including for some, an adult child who temporarily moved into their home, or conversely invited their parents to live with them, to be on hand to offer additional assistance. Having an existing relationship with a named person or service that could be contacted for support, advice, and signposting as needs changed was another mark of distinction. A named, helpful and accessible person, be they an Admiral nurse, a person at a local dementia centre or carers centre, or an accessible GP, provided comfort, reassurance and practical help.

These interviewees reflected on aspects of their social, environmental, and financial circumstances that they felt had made supporting their partner during the pandemic restrictions relatively easier than it may have otherwise been. Better relations with neighbourhoods and neighbours, family and friends; comfortable houses (sometimes renovated with adaptions); gardens and accessible local green space; and a sense of financial security, were often linked to broader options and greater control, and associated with feelings of being better placed to manage and cope with the care deficits generated by the reduction in available support during the pandemic.

This highlights the struggles faced by people without these forms of support, who also felt disconnected from their local communities. Interviewees that did not have an existing relationship with a known person or service, and subsequently felt unsure as to who to contact or where they could access advice, described feeling particularly isolated and concerned about the future:

> *I'm not at that stage, but to be honest, I wouldn't know where to turn if I needed it. I don't feel as if I've got anything that I can turn to and say, "Well, I know I can contact them," or "It'll be easy to get help from..." … There's nothing that's going to help me physically and that is really, really worrying for me that I can look after myself now, just about, but this programme said people with dementia can live twenty years from diagnosis. That would make me ninety. I couldn't be looking after myself at ninety, never mind about [partner]. So I guess it's a lot of worrying about the future, and if you knew there was something in place that would ease that, that you wouldn't have to worry too much. (Interview 16: female carer, aged 74, non-easement area)*

Table 2 shows that most people were getting unpaid help from someone with care (49%), everyday tasks like shopping gardening and cleaning (38%), and emotional support (66%) before the pandemic. Family was the most important source of support in each domain, with friends and neighbours also important for emotional support. Civil society groups (such as community groups, volunteers, religious organisations, Age UK or similar) supported relatively few people, but their support was no doubt very important for those they helped. However, one quarter of survey respondents (24%) reported that they were receiving no help from any of these sources with care, tasks or emotional support when the pandemic began. At the time of the survey, which was approximately two years into the pandemic, there was much less support than before the pandemic from friends, neighbours and civil society groups for most people. Those without sustained potential to call on family, friends, neighbours and civil society groups were left very vulnerable.

Table 2: *Receipt of help from family, friends & neighbours, and civil society before the pandemic and now*

	Percentage in receipt		
Before the pandemic	**From family**	**From friends and neighbours**	**From civil society groups***
Help to care	43	13	12
Help with everyday tasks like shopping, gardening, cleaning	33	9	4
Emotional support	56	33	18
	From anyone		
Some help with care before the pandemic	49		
Some help with tasks before the pandemic	38		
Some emotional support before the pandemic	66		

No help from anyone for care, tasks or emotional support pre pandemic	24				
Change since the pandemic with support for care, tasks, and emotional support:	**Now no support**	**Less support from all**	**The same level of support from at least some**	**More support from at least some**	**Total %**
Family	26	4	34	36	100
Friends and neighbours	52	8	21	19	100
Civil Society*	60	6	13	21	100

Source: Carer Survey; n=604

Note, only people who were still supporting their family member to live at home with dementia at the time of the survey in April - July 2022 were included in survey analysis; survey fieldwork 2 years after pandemic began

*Including community group/volunteers/religious organisation/Age UK or similar

Overall, people were receiving far less formal support two years into the pandemic than they had been at the start

The survey data support the qualitative accounts of it being harder also for people to access formal support and services than before the pandemic. Just over half of respondents reported that they had been in receipt of some form of formal support or service before the pandemic, with some people accessing multiple sources of formal support. The funding of these varied: a quarter of respondents were in receipt of services funded by the local authority, about a half were self-funding or funded with wider family support, a fifth in receipt of services provided by a charity or otherwise free of charge at the point of delivery, and 10% did not know how their services were funded. Bearing in mind that survey respondents were all still supporting their family member to live at home at the time of the survey, respondents in receipt of these services at the beginning of the pandemic were asked how this support had changed.

As Table 3 shows, across each item on average respondents were now getting much less support than before. Of particular note are the reductions in group activities, residential respite and day centre days, but also substantial reductions in social worker support, support from Admiral nurses, and reductions in home care.

> **Overwhelmingly carers reported negative, stressful, isolating experiences, leaving them at breaking point**

***Table 3:** Receipt of formal support and services, before the pandemic and now*

Receipt of and change in formal support and services*	Percentage
Formal support and services pre-pandemic	52
Of people in receipt of formal support and services, these were paid for by:**	**Percentage**
The person with dementia either alone or with spouse/ partner	45
Privately by the wider family	5
Local authority	25
Charity or free of charge	21
Don't know	10

Of people who previously had this form of support before the pandemic, they now have:***	Now no support	Less support	The same level of support	More support		*n=*
Social worker	52	15	18	15	100	*54*
Admiral nurse	38	24	10	28	100	*29*
Helpline	46	4	12	38	100	*26*
Counsellor or therapist	42	5	26	27	100	*19*
GP or community mental health services	30	19	29	22	100	*88*
Group activity for my family member with dementia	28	21	39	12	100	*57*
Group activity for me	70	13	7	10	100	*30*
Group activity for both of us	61	10	21	8	100	*72*
Befriending or visiting service	55	17	17	11	100	*18*
Home care or domiciliary care	31	4	36	29	100	*98*
Meals on wheels/laundry/cleaner	38	14	34	14	100	*29*
Sitting service	43	14	24	19	100	*21*
Respite days in a residential home	89	11	0	0	100	*18*
Day centre days	48	19	17	16	100	*69*
Lunch club	47	20	33	0	100	*15*

Source: Carer Survey; n=604

*including social worker, Admiral Nurse, Counsellor, GP/Community mental health services, group activities for family member/self/both, home care, meals on wheels/cleaner/laundry service, sitting service, respite days in a residential home, day centre days, lunch club visits

**multiple boxes could be ticked as some people used a range of services

***Note: only people who were still supporting their family member to live at home with dementia at the time of the survey in April - July 2022 were included in survey analysis

> **Only a tiny proportion of survey respondents – less than 1% – were contacted at least once a month by someone from a service, agency, or the local authority to find out how they were managing**

Impacts on carers

Overall, the profound impact on carers was in the relentlessness of the caregiving role. They were unable to take any kind of break or time for themselves. They described exhaustion, depression, things piling up, that their usual sense of stability had been disrupted; feeling of irritability, tension, and several referred to the 24 hour a day nature of caring in the pandemic, "just so hard", "just difficult, just so difficult". Interviewees described intense feelings of isolation and loneliness – even though some carers had already been experiencing isolation prior to the pandemic, the situation had been compounded.

There is a profound sense of distress through the interview data, as in this excerpt:

> *I think that was the main thing, the loneliness. Not just being able to escape. .... I think it was the loneliness... So it's not like he was going to respite and I lost that, or he was going to clubs that he wasn't able to go, he's always been around, so I think it was the frustration for him probably and the loneliness for me was the biggest impact. (Interview 16: female carer, aged 74, non-easement area)*

Some carers found that they were cut off from community health services just when they needed them most, when their partner's needs were escalating, including for example incontinence services and district nurse support. Many described having experienced feelings of low mood, depression, and anxiety. Several carers reiterated that they were unable to distinguish the impact of the restrictions arising from the pandemic from the overall impact for them of their partner's progressing dementia, but that cumulatively these experiences had been very emotionally difficult to manage, such as in these examples:

> *For me, I'll tell you what, mentally I've never been so down in all my life. I've been in some black places, I'll tell you. I won't say suicide is a thing I thought. I did, but I thought, how do people – how do people cope? (Interview 7: male carer, aged 77, non-easement area)*

> *Dare I say, a nightmare. Um… I think I have changed my whole persona in that where I was outgoing and happy person, I've become more tense, more weepy, more unhappy. Half glass – isn't full any more, it's right down to probably a quarter of an inch. Life isn't the happy, outgoingness I used to have. (Interview 23: female carer, aged 85, easement area)*

Several carers also felt that caring for their partner alone during the pandemic had had a detrimental impact upon their physical health, for several this had culminated in an admission to hospital and breakdown of the caring arrangements, which either they or their medical professionals had attributed to stress, such as in this excerpt:

> *What came out in the end of it all was that my heart was okay, all I was suffering from was tension and pressure and stuff like that. And that's why [partner] is in respite now, because that's what they thought was causing it, so the pressure of looking after her, had this effect on me. (Interview 2: female carer, aged 82, non-easement area)*

Several carers described having additional caring responsibilities for another member of their family, such as a parent, sibling, child, or grandchild, and highlighted a general lack of awareness and recognition that as an older person caring for a spouse, they may also be providing significant support to another family member, either also co-resident or living away from their home. The impact of these responsibilities was often described as cumulative and difficult to balance. The pandemic significantly heightened difficulties in this respect as carers felt either compelled to withdraw the in-person support that they provided to their other relative due to concerns regarding Covid transmission or lockdown rules, or to attempt to continue to support both parties at a detriment to their own well-being.

Carers noted that they had perhaps not fully recognised the extent of the stress that they had been experiencing, or their need for additional support or periods of respite. In these instances, it was often family members or health professionals that triggered and instigated changes or intervened and insisted on respite, for example illustrated here:

> *I mean what my family have said to me. I mean I'll be honest, I still didn't want [partner] to go into the home or anything else, I wanted to plod on, but like they've said if I don't look after myself I can't look after her, so what I'm doing is what my family have told me to. If this works out what they're saying is I should do it on a sort of regular basis. (Interview 2: male carer, aged 82, non-easement area)*

> *Well, this nurse saying, "Right, you know, you're going to fall apart, because obviously, you know, you're doing this solely on your own." And this is where they said, "Right, so we need to get him into a place for a fortnight's respite, so it's respite for you." (Interview 31: female carer, aged 75, non-easement area)*

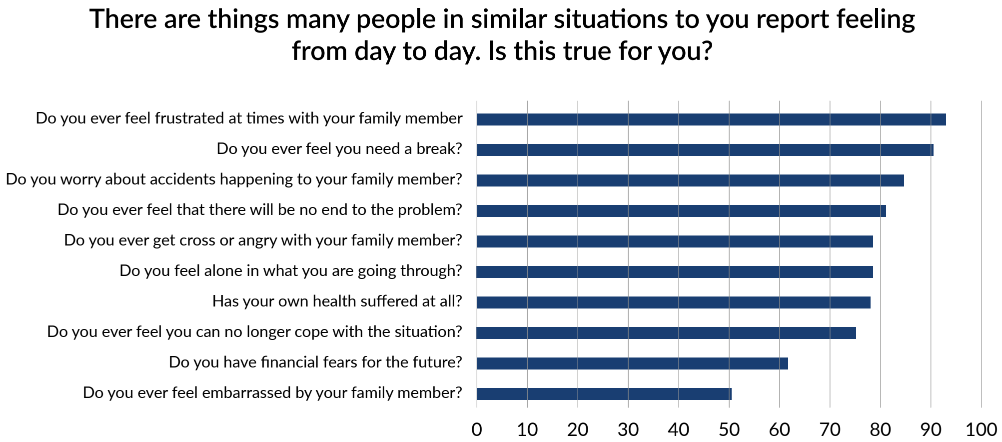
Finances were a terrible worry for some, especially if they had savings not far above the £23,250 threshold for local authority funded support. Anxiety about being able to pay for and have a choice over "good" residential care for their partner in the future came up for several carers, and some felt unable to pay for ongoing care after the six weeks offered by some local authorities without financial assessment after hospital discharge had ended. One 80-year-old interviewee had support from homecare four times a day (meaning an assessment at a high level of need) but felt that he would not be able to continue with this level of support after the six-week period. The later interviews took place after energy costs had started to rise which was an additional concern, with one carer explaining that with petrol and heating costs on top of the costs of care, she could not afford to go to a one-hour weekly singing group due to the additional cost of the three hours sitting service that would be needed. There was a great deal of anxiety about what would happen as people, some of whom were fast spending their dwindling savings, approached the £23,250 savings threshold, with no information available and no-one to turn to, to understand how that transition would or could work.

Survey measures of wellbeing and mental health

The survey results in Figure 3 and Table 4 confirm a population in acute distress in terms of wellbeing and mental health. Formal measures from the survey include the Relatives Stress Scale,[31] the SIDECAR instrument measuring quality of life for carers of family members living with dementia on a scale of 1 - 100[32–34], the Generalised Anxiety Disorder assessment (GAD-7) with a standard threshold score of 10 used to define clinically significant symptoms,[35] and symptoms of depression using the abbreviated Centre for Epidemiologic Studies Depression (CES-D) Scale with four or more depressive symptoms indicating elevated depressive symptoms showing a risk of clinical depression warranting further assessment.[36–38] We also use the short version of the Revised UCLA loneliness scale with scores of 6+ indicating loneliness. [39] Full details of these measures are contained in Appendix 5.

Figure 3 shows items from the Relatives Stress Scale. Over 90% of respondents indicated that they feel frustrated with their family member and need a break, with more than 80% worrying about their family member and feeling there will be no end to the problem, and more than 70% saying that they feel they can no longer cope with the situation and that their own health has suffered. This is reflected in the very high scores recorded in the survey for poor quality of life, anxiety, depression and loneliness shown in Table 4. By way of comparison for example, in the English Longitudinal Study of Ageing measuring population statistics for the over 50s, 23% of people met this threshold for high loneliness in the ELSA Wave 1 Covid sub-study, 9% met this threshold for high anxiety, and 22% for depression (author's analysis). This compares with 57%, 37% and 66% in Table 4 respectively. Notably also, while 66% of the survey respondents show risk of clinical depression, a quarter of respondents (26.5%) had the very highest scores of 7 or 8 (out of a possible 8) on this measure; and 18% met the threshold of a score of 15+ for severe anxiety. Table 4 also shows that on each measure, the mental health and wellbeing of co-resident carers was substantially worse than for those living elsewhere. Notably, for co-resident carers, 71% exhibited symptoms indicating clinical thresholds for risk of depression, 40% displaying anxiety that indicates clinical investigation advised, and 62% scored more than 6 points on the UCLA loneliness scale.

***Figure 3:** Relatives Stress Scale questions*



Source: Carer Survey, n=517

***Table 4:** Mental health and wellbeing: results from the carer survey*

Mental health and wellbeing: results from the carer survey			
	Mean	Standard Error	*n=*
SIDECAR measure of quality of life for carers of people living with dementia	56.9	1.2	*516*
	Percentage		
Elevated depressive symptoms	66		*450*
Moderate or severe anxiety	37		*498*
Lonely	57		*515*
Source: Carer Survey			

	Co-resident	**Lives elsewhere**	*p=*	*n=*
Elevated depressive symptoms	71	59	*p<0.01*	*449*
Moderate or severe anxiety	40	33	*p=0.08*	*497*
Lonely	62	48	*p<0.001*	*514*
Source: Carer Survey				

The most difficult things

Survey respondents had the option of a free text question at the end of the survey 'What has been the most difficult thing for you and your family member during the pandemic?'. The themes from the qualitative interviews were confirmed at scale, with isolation and loneliness for both carers and their family member living with dementia a profound problem, as well as being confined together 24/7 with no respite and no other interaction. There were numerous comments describing worry and anxiety regarding the risk of contracting and transmitting Covid to the person living with dementia. Mirroring the interview data, the perceived accelerated decline of their family member's cognition and physical health due to the closure of services and social activities and the subsequent reduced opportunity to socialise, interact, and be physically active, was frequently cited; as were difficulties in accessing support, navigating services, and the lack of any options for support.

Survey respondents also documented the increase in their caring responsibilities due to the lack of outside support. Seventy-two per cent of survey respondents said that the amount of support they provide to their family member had increased since the Coronavirus outbreak. Carers cited the challenges and emotional burden of needing to repeatedly convey the pandemic and the pandemic restrictions to their relative, and their relative's difficulty understanding and retaining this information. For those not living with their family member, the separation during the pandemic presented many challenges, as well as the problems of multiple caring responsibilities in networks of family care.

Several respondents to the survey raised financial concerns and the perceived inequalities in access to care and care quality arising from financial means, with worry, anxiety, concern, and despair being expressed at the financial costs of care. Several comments concerned difficulties and implications of struggling to access financial support and benefits.

The survey respondents and interviewees were also asked whether anything good had come out of the pandemic for themselves or their family member. Several carers noted that in some respects the pandemic restrictions had been helpful to them, as the limited opportunities to socialise and engage in outside activities had acted to quell some of the difficulties that they had begun to experience prior to the start of the pandemic due to the progression of their partner's dementia. The sense of loss relating to diminishing social engagements was not felt so acutely because most of society was now also restricted. Some were relieved at no longer having to socialise because of the stress that socialising with a family member living with dementia carried. Some survey respondents reported renewed insight into their own resilience, others that they had learned the limits of their abilities to cope and acceptance that they needed outside help, and some reflected on the slower pace of life being helpful. Some interviewees and survey respondents reported closer family relationships, that they had had more time with family members – often because of the furlough scheme – and the benefits from forging new connections with neighbours and communities. A very small number of survey respondents (less than 10 out of 600+) mentioned improved technical skills with online services and social connections such as via Zoom.

For younger carers responding to the survey supporting a parent living with dementia, flexible working and working from home enabled them to combine work and caregiving. However relatively few people responded to this question at all, and many used it to emphasise that nothing good had come of it, and their experiences had been awful.

Summary of carer experiences

In summary, older carers supporting people with dementia living at home did not experience the pandemic differently in easement and non-easement areas, but across areas the impacts of the reductions in local authority, community, third sector, and private support and services on the carers in our study were profound. The pandemic exposed existing fractures in the care of older people at home, exacerbated these, and added new ones. Carers related pre-existing structural and systemic problems with post-diagnosis support, and the lack of interaction and connection between diagnosis, the progression of the disease, and pathways of support. During the pandemic, there were problems reported enlisting any help or assessment from local authorities, especially for self-funders, and in navigating the minefield of support and care provision. There was widespread reduction in residential respite and home care provision (albeit the latter commonly at the request of the carers), suspension of day centres and day services, closure of support facilities and suspension of befriending and in-home sitting services. Principal Social Workers/Safeguarding Leads and carers alike reported high levels of isolation and loneliness for carers, difficulties in accessing support, perceived acceleration in cognitive and physical decline, and declines in caregiver mental and physical health.

Services and support were not being delivered in the same way or to the same level available pre-pandemic, or in some cases at all

On the face of it the evidence from carers above indicates that services and support were not being delivered in the same way and to the same level available pre-pandemic, or in some cases at all. Interviews with Principal Social Workers and Safeguarding Leads confirmed that this was the case across easement and non-easement areas. Although the easements were only invoked by eight local authorities, the professionals from the other 15 local authorities around England interviewed for this study reported similar anxieties and made similar decisions relating to reduction of services and changes in services to cope with pandemic conditions.

Local authorities prioritised those with highest needs and in crisis, but typically, in both easement and non-easement areas, Principal Social Workers/Safeguarding Leads confirmed that much home care reduced, day centres closed, support services moved online/over the telephone, assessments moved online/over the telephone, and several services were re-prioritised to support frontline delivery. Respite care reduced substantially, both in terms of in-home sitting services, day centres, and residential respite. It is also suspected that written records of assessments were not sent out by post due to the physical closure of buildings; and people in a number of areas were also not being offered choice of residential care homes.

In the remainder of this report, to preserve anonymity we refer to the Principal Social Workers and Safeguarding Leads who we interviewed as PSW/SLs without further specificity, nor do we mention the local authorities they came from. We have also made the decision not to present direct quotations from PSW/SLs as we consider that such quotations might be disclosive of respondents, which would potentially breach our ethical requirement for anonymity.

Reductions in home care, service-users declining services, and furlough

One easement local authority told us that once easements were enacted, they reviewed all care packages with lower risk users (with users' consent) to suspend or reduce care provision, informing service users that this would potentially be for two to three months before being offered reinstatement. Some carers in the survey in both easement and non-easement local authorities reported their service provider informing them that care would no longer be available because of the pandemic. However, the more common experience of local authorities, confirmed by the PSW/SL interviews, our carer interviews, and the survey, was that service-users themselves cancelled their care packages because of the risks to health and life that having home care workers coming into their homes presented. This was widely reported across easement and non-easement local authorities. Some non-easement local authorities reported that without this 'slack in the system' caused by unexpectedly reduced demand, their local authorities may have had difficulty coping, and/or would have been compelled to enact easements. This situation was greatly and, again unexpectedly, eased by the furlough scheme, with family members and the community suddenly available to step in to help with sometimes extreme care needs of older people.

It is therefore likely that the system was only able to function because many older people in need of home care, and who had been formally assessed as such, declined to have home carers in their homes because of the extreme risks to health and life that they faced from these carers. Demand thus substantially reduced, even though these were people with high levels of care needs. This left a care deficit, which in some cases was filled by workers on furlough who could suddenly help to support family members living with dementia at home, an unintended positive and opportune consequence of the furlough scheme. Without furlough, local authorities and people needing care would have been in much more trouble and even with the loose interpretation of statutory duties under the Care Act that ultimately prevailed (see below, page 32), more would likely have been compelled to invoke easements. This would likely have had serious consequences for people needing care. However, where there was no furloughed family, without home care the caring burden on the carer undoubtedly increased. Indeed, 72% of survey respondents said that the amount of support they provide to their family member had increased since the Coronavirus outbreak. Given that little follow-up with families was reported (see next paragraphs), it is not known what happened to care deficits or the wellbeing of those being cared for or carers in these cases, nor indeed what happened when furlough ended.

Many described having experienced feelings of low mood, depression, and anxiety

What happened once services had been withdrawn varied somewhat, but many local authorities reported, and our interviewees and survey respondents confirmed, that once home care and support had been declined (by carers in an impossible position), there were few instances of follow-up by local authorities. This is despite those families having previously been assessed as having eligible and unmet needs. A common response from local authorities was to confirm in writing that care had been withdrawn at the request of the service-user and leave the service user to get back in touch with the local authority as and when they felt it appropriate. People were largely left to their own devices from then on in, left to contact the local authority if in need. This is in a client group that most consider to be invisible and unlikely to seek help if needed, often only coming to the attention of service providers in a crisis when the extent of unmet need suddenly becomes visible to those outside the household – for example a crisis hospital admission.

PSW/SLs also told us that they often only became aware of older caregivers and people requiring care in need because of referrals from GPs, or day centre or other voluntary staff who become concerned about a family. But this withdrawal of care and follow-up was happening at a time when these normal routes to local authority attention were not functioning.

What happened to these families, who had previously been assessed as having needs requiring additional support (either for the person living with dementia, or the carer, or both), remained largely unknown. Yet if a co-resident older carer took on the care deficit, inevitably and logically at the very least the carer's own need for support increased, and likely the person living at home with dementia too. This would have been compounded by the emerging evidence that those living with dementia were fast deteriorating physically and mentally in the pandemic. The increase in the carer's needs should have been self-evidently apparent, triggering a local authority duty to assess or review need under s10 or s27 of the Care Act (our emphasis):

> Section 10(1): "Where it **appears** to a local authority that a carer may have needs for support (whether currently or in the future), the authority **must** assess…"
>
> Section 27(4): "Where a local authority is satisfied that **circumstances have changed in a way that affects** a care and support plan or **a support plan**, the authority **must**—
>
> (a) to the extent it thinks appropriate, carry out a needs or carer's assessment, carry out a financial assessment and make a determination under section 13(1), and
>
> (b) revise the care and support plan or support plan accordingly."

Interestingly, none of our PSW/SLs or other local authority interviewees reported an increase in carer assessments being offered in the first year of the pandemic, as one might logically expect given the nature of the statutory duties in ss.10 and 27 of the Care Act.

PSW/SLs reported doing what they felt they could to offer alternative provision. Some suggested that they had segued successfully to alternative provision, particularly for closed day centres, including in the more extreme cases of need, one-to-one provision, and making more use of community networks. Local authorities reported the one-to-one provision particularly being at considerable financial cost to them ("costing an absolute fortune"). Further, whilst they were paying for this alternative support, they were still paying for day centres and day services even if they were not open, because they could not afford to have them close permanently and needed to maintain stability in the care market.

Local authorities also reported forging closer connections with community services and communities, and some saw the potential to build further on community links in the provision of social care following the pandemic. Many day centres and support services were moved online or into virtual environments which some PSW/SLs thought was superior in many instances and even preferred by some of those using the services.

PSW/SLs also expressed optimism about people being able to use Direct Payments to fill in gaps (but acknowledged that this was not necessarily helpful to our participant age group for a variety of reasons).

Despite the optimistic view of some PSW/SLs of their alternative provision, as noted above the experiences of carers receiving diminished services were almost universally negative and the lack of respite that the day centres, support services, and residential care respite had provided was and remained a very serious problem. Furthermore, many day centres and day services remained closed even at the time of our interviews in mid- to late 2021, more than a year into the pandemic; some were slow to re-open after the easing of social distancing measures, and where they did, this was often at reduced capacity.

Most of the local authorities that we spoke to, confirmed by carer interviews, increasingly struggled with ensuring consistent home care provision and governance of home care as time went by in the pandemic. This was partly because of the commissioning process and lack of control over staffing by commissioned providers. It was also because of the exodus of home care staff, with people leaving to go to the retail, leisure and hospitality sectors, where they received better pay, better perks (e.g. discounts for shopping), consistent hours, paid for all the hours they work (a problem in the home care industry), less demanding work –physically and emotionally – and less risk. This has implications for the pay, terms and conditions of the social care workforce, and particularly how this might be protected or enhanced in crisis circumstances.

Nearly all local authorities in our study, in both easement and non-easement areas, moved their Care Act assessments from ‘in person’ to remote assessments. One PSW/SL also confirmed their local authority who had invoked easements also shortened their Care Act assessments. Remote assessments involved a variety of methods including telephone calls, video calls, MS Teams, WhatsApp, and Facetime. Several local authorities made this change based on government guidance that face to face was only to happen if it was absolutely necessary. As noted above, people were reluctant to have others visit their houses because of the Covid dangers and remote working did cater for this.

However, this change to assessment delivery can be contrasted with Mental Health Act assessments which after a legal challenge in January 2021 had to be undertaken in person regardless of the pandemic.[40] For older carers and older people living with dementia at home, local authorities acknowledged multiple challenges with remote assessments. These included with the technology itself, challenges faced by people with cognitive difficulties and sight and hearing impairments, but also the loss of the ability to see or hear for themselves what the situation was in the home.

Meeting in person was therefore much more than just communicating in words; it also allowed for a closer intimacy in discussions than could be achieved remotely. This was viewed as especially important for a client group where people had a tendency to say they were managing even if they were not. There was a clear aspiration that face-to-face assessments resume, particularly for this category of carers.

Many (but not all) local authorities reported a general worrying dip in safeguarding referrals for people living at home during the lockdowns as well as a reduction in reported cases of neglect in care homes attributed to relatives not being permitted into the homes. Whilst not necessarily specific to our group of carers, there was also a corresponding general increase in cases such as self-neglect and domestic abuse after the lockdowns ended and at the time of interviews in mid-2021. Some suggested that the referrals being received once the lockdowns had been lifted were more complex and serious.

Hidden carers

Whilst a number of local authorities had adapted their methods of delivery, many local authorities confirmed that difficulties arose because many carers who were struggling remained unknown to them and often did not come to the attention of the local authority until crisis point. As confirmed by one PSW/SL ‘they only knew the ones they knew’. Issues could gather speed very quickly for this group of people with size of care package not necessarily a good indicator of care needed. This is exacerbated as spousal carers often do not identify with the word “carer” rendering a mismatch between language and need. All of this is further compounded by perceived stoicism in older generations, and cultural stigma around the symptoms of dementia. There may also be fears about the consequences of coming to the attention of services, particularly during the pandemic, with risks of separation, deterioration, and death if someone went into respite or permanent residential care.

Some local authorities however were looking actively to identify these hidden carers by working with mental health services, Admiral nurses and employing carer support workers particularly to work with older carers. One local authority had recognised the need to prioritise unpaid carers focussing on trying to do small things to help. They had introduced a priority badge for supermarket queues, a dedicated post to complete carer assessments, flexible support including emergency 24-hour in-home support for up to 72 hours in a crisis, and a package of one-off 25 hours that people could access as they needed. But even with such innovative approaches, local authorities were worried that carers in trouble were not coming to their attention. One PSW/SL expressed their concern that the numbers of carers coming to their attention had dipped in the pandemic suggesting they were a cohort that they were not managing to find and reach. This is particularly pertinent where social and medical in-time support might prevent a breakdown of carer arrangements, thus heading off much more traumatic and potentially expensive crises down the line.

The difficulties for self-funders in getting beyond a triage question as to their finances referred to above (see page 21), suggests that carer assessments were routinely not being carried out even where carers tried to reach help. This is despite a duty in law for local authorities to assess carer needs regardless of means (paragraphs 8.50 – 51 of the Care Act Statutory Guidance). The evidence from this study suggests this legal duty is commonly misunderstood. This means that older people in trouble are not formally coming to the attention of the local authority or accessing services that might help. Since it is believed that older carers often do not seek help even when needs are not being met, when people do seek help, things are probably serious. It also can be financially perverse sometimes to charge carers as they might then refuse support which could lead to carer breakdown, followed by local authorities having to meet more eligible needs of people that would otherwise have been cared for voluntarily.

> **In all likelihood, local authorities temporarily rationed social care out of necessity, but the majority did so without legal protection**

Legal interpretation: were Care Act easements likely to have been required?

To the extent the issues reported above look like they were, or might risk being, derogations from statutory duties at least in some instances for some people – including for assessment, provision, communication, and reviews – on the face of it Care Act easements were likely to have been required. If in any individual case a local authority was unable to assess those who appeared to be in need, or could not meet eligible needs, or could not offer alternative arrangements to meet anyone's eligible needs, or could not give written records of assessments, their statutory duties were breached without the protection of easements. Although there may have been 'cogent reason' justification for departing from statutory guidance in an individual case, the statutory duties remained absolute. Questions remain as to whether and how local authorities that did not invoke easements, or after easements had been revoked, might be said to comply with their Care Act duties if:

- the inevitable increase in the appearance of need for care/support could not be assessed (Care Act ss.9-10);
- the eligible needs of the cared-for person could only be met by attending a day service which was closed or by home care services which could not be provided in a safe way or at all (Care Act s.18);
- the carer's eligible need for respite could only be met by the cared-for person attending a day service, having a sitting service at home, or being in short-term residential care which was not available (Care Act s.20);
- the carer's eligible need was for a befriending service, or support or activity group to alleviate loneliness and social isolation, which was not available (Care Act s.20);
- the change in circumstances affected a care/support plan but no re-assessment and revision of it could practicably be made (Care Act s.27);
- when office buildings were closed, a written record of the Care Act assessment could not be given to a person who did not have access to (secure) email (Care Act s.12(3)-(4)).

Unless local authorities could guarantee that none of these things had happened at all, to anyone, easements were required. Given the weight of the evidence set out above in pages 13 - 28, it seems unlikely that such a guarantee could be given. In all likelihood, local authorities temporarily rationed social care out of necessity, but the majority did so without legal protection.

This raises the question why this happened this way.

Interpretation of the easement legislation across local authorities

Although the experiences were similar across the local authority areas in this study, easements were differentially implemented, and soon revoked.

Not all eight local authorities enacting easements initially publicly revealed their reasons for doing so. Reasons given in interview varied but the most common were the actual or anticipated diminishing capacity of the workforce and the need to reprioritise services, with closure of day centres, inability to send written communications by post, inability to offer choice of care home providers or preferred accommodation, and inability to offer annual reviews all being mentioned. Many of these issues were common across all the local authorities in this study, in both easement and non-easement areas. It thus quickly became clear that although there were variations in challenges across the country, particularly around the provision of day and home care and the pandemic conditions themselves, the main difference between easement and non-easement local authorities was not in the challenges that they faced, nor in the ways that they faced them. Rather it was in the legal advice that they received as to whether the actions they were taking were likely to put them in breach of statutory duty, or whether they were legally protected. Indeed, a factor for at least one local authority that invoked easements was their belief that they were likely to face a legal challenge if they did not do so.

Some local authorities had feared workforce reductions from the pandemic that led to easements, but not all local authorities that enacted easements because of feared staffing shortages suffered such shortages; indeed, most reported that during the easement period they had lower than usual sickness rates and good staffing levels. This was attributed to the ability to work from home and the dedication and resilience of the workforce in the face of adversity. One easement local authority did however suffer staffing problems, believed to be related to having a workforce that was older, with providers' staff predominantly drawn from one minority ethnic group at high risk from the pandemic and employed on zero-hour contracts over which the local authority had no control.

Confusion about the need for easements was widely reported. One PSW/SL reflected on the lack of clarity around the implications of social distancing and closure of day services for Care Act duties. Easements on their analysis were enacted for these reasons. They had queried the legal position with the Department of Health and Social Care and had been referred to the interim Chief Social Workers for Adults in England. The local authority believed it had been suggested to them that easements were not needed even though alternatives to day services could not be offered. A request was made for this to be put in writing, but this confirmation was not forthcoming, putting the local authority in an invidious position. Another PSW/SL from an easement local authority described a PSW meeting with one of the interim Chief Social Workers seeking clarity about whether they needed to continue with easements but received no answer and conflicting opinions from those in attendance.

Government communication was largely seen as helpful, especially the ethical framework [see Appendix 1]. This supported decision making, but because of the rapidly changing environment, information could also be contradictory, inconsistent, changing, confusing and overwhelming. Professional networks on the other hand, such as the ADASS and PSW networks, were seen as extremely important for senior leadership in staying connected and for decision making in the crisis conditions of the pandemic. This was facilitated by technology and virtual platforms. These became a forum for sharing information about risk and best practice, becoming vital places for discussion and interpretation of national information. These forums potentially explain some of the regional variation in the invocation of easements concentrated around the West Midlands. It might also be material that three of the eight local authorities who enacted easements had carried out pandemic planning exercises a few months before Covid hit, and whilst not social care specific, discussions had been held over what might be required in areas such as prioritising staffing and adapting services. Regional discussions worked in both directions however. At least one of the easement local authorities believed they would face potential legal challenges if they did not enact easements and interpreted the legal position as quite 'black and white', but then with the benefit of their experience after enactment detailed below, talked about the 'can of worms' that could be created from changing from easement stage 2 to 3 – experiences which were also shared with the networks. These networks are likely to have played a part in the invoking of easements among local authorities and may also explain why other local authorities may not have followed suit once the adverse publicity and negative attention on those who had done so were shared.

> **The main difference between easement and non-easement local authorities was not in the challenges that they faced, nor in the ways that they faced them – rather it was in the legal advice that they received**

In the light of what local authorities actually did, therefore, the legal interpretation of the need for easements varied widely. While one local authority thought that the closure of day centres and day services (often at the heart of meeting the needs of both the cared-for and their carer) necessitated the invocation of easements, others had not seen this as a reason. Conversely, some who invoked easements did not see day centre closure as related to easements. Guidance on this point was opaque although the PSW/SL from one easement local authority suggested that the interim Chief Social Workers were reported to have indicated that this would not necessitate easements, even if an alternative was not offered. Even where an alternative (such as a telephone call or an offer of an online group) was offered, whether this could meet the needs of people living with dementia and their carers remained open to question. Some local authorities reported having put in one-to-one support to some vulnerable people at high cost to replace day services as necessary to meet what they viewed as their statutory obligations, but others did not. Some saw potential problems with home care providers as necessitating easements, but others did not. Some saw problems with posting written communication as necessitating easements but although others did not mention this, it is suspected that they too may have struggled to provide posted communications without seeing these as relevant to easements. Some cited the inability to provide a choice of residential care providers as necessitating easements, but others also reported this difficulty including in non-easement areas – with one specifically reporting that they did not see this as a reason to invoke easements. Many local authorities across easement and non-easement areas reported residential respite care being closed or substantially reduced but despite no real alternatives for carers assessed as needing respite, none cited this as a reason for invoking easements. One cited the diversion of staff from reviews to providing front-line services as a reason for easements; others may have done the same in easement and non-easement areas but did not see this as a reason to invoke easements.

Responses to the easements

There appear to have been no consequences, either political, legal, or regulatory, for local authorities that did not enact easements. However, there were stressful consequences for the local authorities that did.

There was swift recognition by policy actors that easement decisions needed political support and public endorsement. The whole environment was highly politicised. One non-easement local authority PSW/SL reported how their local MP had sought to dissuade them from enacting easements. Easement local authorities also faced attacks from the media, lawyers, and charities, over their decision. Several local authorities faced freedom of information requests, letters before action or legal challenges to the invocation of easements, including judicial review. PSW/SLs felt in an impossible position, between facing adverse media, civil society and public pressure or potentially ending up in court for non-compliance with duties under the Care Act. Two of the PSW/SLs from local authorities that enacted easements referred to an article which had been published in which it appeared that one of the interim Chief Social Workers had been critical of local authorities that had invoked easements.[41] Whilst the interim Chief Social Workers later advised that this was a misquote, the PSW/SLs expressed their disappointment and to a degree, feelings of betrayal, by the stance relayed in the article. One described it as 'being thrown under the bus' and this had been particularly dismaying as they had aspired to be open, transparent, and honest by enacting the easements.

Easements could also be misunderstood internally within local authorities, with some frontline staff and managers in one local authority wrongly blaming easements, rather than pandemic conditions, for the reduction in service levels. This was despite local authorities trying to communicate precisely what easements were, what was being done and providing clear guidance. This was recognised as a danger at an operational level: that easements could potentially be used as a standard excuse for not providing a service.

Evidence from local authorities where easements were invoked suggests that the social care leadership took such derogations from usual care extremely seriously, in the face of unprecedented circumstances. Several of our professional interviewees expressed surprise, even shock, that other local authorities had not invoked easements when they could see that they were facing the exact same challenges and taking the same types of mitigations to meet them. One PSW/SL from a local authority that invoked easements reflected that local authorities who had not enacted easements but were (as perceived) also not complying with Care Act duties, were not being held accountable. Conversely, some PSW/SLs from non-easement local authorities suggested that the easement enacting local authorities had 'jumped too quickly'. While for the easement local authorities, the purpose of enacting the easements was not to neglect people but to be able to prioritise fairly, transparently, and lawfully the most vulnerable, the public narrative of easements focussed on human rights being infringed, rather than a more positive narrative around being transparent, shifting priorities to the frontline, urgent work, and keeping people alive.

Easement local authorities felt that more could have been done nationally to protect them, including the subsequent damage to their reputations from the negative press. The widespread criticism did not acknowledge the immense financial and operational strain that local authorities were operating under, nor the legal confusion. The situation led to distress and dissatisfaction within the leadership of the local authorities that invoked easements, who felt very strongly that they were doing the right thing, the ethical thing, the moral thing, and acting in the spirit of the legislation, by transparently invoking easements when there were aspects of usual care that they believed they were legally bound to provide pursuant to the Care Act, that they became unable to provide. They felt pilloried and attacked. This created disincentives to the very transparency and accountability envisaged by the easement regime. For those that did, opinions were divided as to whether, faced with the same circumstances, they would do the same thing again, but all reflected that the challenges that they had experienced, and for at least one local authority, the overwhelming burden of paperwork and bureaucracy associated with the easements, would be part of any future decision-making matrix.

It is hardly surprising in this atmosphere that so few local authorities invoked easements. Many of the non-easement PSW/SLs had quite negative perceptions of easements, seeing them as delaying meeting people's needs to the point where it could be quite dangerous to do so, with an increased risk of self-neglect and carer breakdown without support. The concern was that easements 'turned duties into powers and musts into cans'. In the same way that some easement local authorities expressed surprise that others had *not* invoked easements, those that had not invoked easements, who could also see that they were not necessarily acting differently from the easement authorities in their departures from usual care, were surprised at the local authorities that had. This reflects the prevailing confusion as to what circumstances, and what changes in social care support, warranted the invocation of easements.

Apart from this confusion, there was resentment and low morale at the differences that the easements implied between the way Health (the NHS) and Social Care were treated and this was evident throughout discussions across easement and non-easement local authorities. Health was perceived as being able to make rationing decisions without statutory intervention or the political and public pressure that local authorities were subject to as a result of the easement policies. One PSW/SL in an easement local authority reflected on the different legal duties that social care faced in contrast to health, and how the health service could re-prioritise services, often resulting in people having to live longer in pain, without the need for anything such as easements and the consequent challenges that followed.

There was a perception that social care was seen as not valued and receiving less investment than health, with little support. This relationship was further impacted by action taken by health having negative impacts upon social care. For example, government backed funding to hospitals to discharge people to free up beds hugely impacted on the demands on home and residential care providers, as well as the local authority resources needed to assess all these people's needs. Many in social care saw what was happening during the pandemic as a prioritisation of health to the detriment of social care. The lack of PPE at the beginning of the crisis and the need for the vaccination of social care staff also caused significant resentment, as did nurses and doctors receiving a pay increase whilst social care had faced a pay freeze. There was no recognition of how, with proper resources and investment, social care could do early preventative work to stop people ending up in hospital and save future health costs.

Revoking of easements

As much as reasons varied for invoking easements, mechanisms and reasons for coming out of easements also varied across the easement local authorities. For some, they did not come out of easements until they were satisfied that specific conditions that in their view had led to easements no longer prevailed – although as already noted many pandemic mitigations continued for a long time, and as noted below, in many instances stresses on the social care workforce increased after the easement period rather than decreased. For others, a decision that things were not going to be as bad as they feared led to revocation, and for one, the negative attention plus a realisation that they were not behaving differently to local authorities that had not invoked easements – apparently without consequences – meant that they could interpret their situation as no longer requiring easements.

Summary

In the crisis circumstances of the pandemic, the operation of the Care Act and associated Guidance was unclear, interpreted differently across local authorities, and was never legally resolved (although Ombudsman decisions [see **https://www.lgo.org.uk/adult-social-care**] provide some insight). The easements unfolded in an atmosphere of political crisis, were very short-lived, and one year after they were last invoked the legal protection to ease was removed.

Have Care Act statutory duties been permanently undermined?

One inference to be drawn from these research data is that the pandemic conditions look to have set a precedent whereby diminished provision has been provided to caregivers and the people they support, below the levels previously thought to be the minimum acceptable, without litigation or regulatory intervention or consequence. This was due to stretched resources and the complex conditions that prevailed, but if it is correct that this could have been done without Care Act easements, then Care Act statutory duties may have been permanently undermined.

The way easements evolved in real life meant that perversely, there was very little logical reason for any person or lobby group to challenge a local authority's decision to reduce the provision of usual care without invoking easements. Rather, the incentives on individuals and lobby groups were to challenge the invocation of easements (with the expressed aim of preventing a watering down of statutory duties by local authorities).

This played out as follows:

- there was at the time a wide variation in legal advice in how far Care Act duties could be 'flexed' under existing Guidance to reduce local authority obligations to provide care and support to meet needs in the unprecedented conditions of the pandemic;
- suppose a local authority reduced its provision without easements – for example, was unable to offer respite care, or closed its day centres, or reduced sitting services and support groups, or failed to assess or review carers with apparently increasing or increased needs; if in an individual case a person or lobby group were to challenge the lack of provision as breaching Care Act statutory duties, the only logical and likely result would have been for that local authority (and others, noticing what was happening) to invoke easements to defend such claims; it would not have resulted in the provision being enhanced or reinstated;
- while this would have led to more scrutiny of decisions under the Coronavirus Act easement regime, it would not have led to enhanced care; there were thus no incentives for people needing care to challenge local authority reduction of provision in the absence of easements;
- indeed, the incentives operated against doing so for fear of easements providing a framework within which further or even deeper cuts could be made, and potentially spreading across even more local authorities;
- the politics of easements thus led to unchallenged decision-making that provision could be reduced without easements, and that all these changes could be made under the existing provisions of the Care Act and Guidance, despite great changes to local authority provision because of the pandemic.

The Coronavirus Act easement provisions could have provided local authorities with a legal defence to a suggestion that reductions in provision led to breaches of the Care Act, but the realpolitik of the situation meant that by 6th July 2020 while local authorities across England had indeed reduced provision and services in response to pandemic pressures, there were no easements in operation and even though the easement legislation was technically in force for another year, none were ever invoked after that. Local authorities may have exposed themselves to litigation by not invoking or retaining easements in the face of reductions in services, but thus far (to our knowledge), no such litigation emerged apart from adverse Ombudsman decisions. This resulted in hidden and less transparent approaches to prioritising services.

Since derogations from usual care were widespread and were ultimately interpreted without challenge (so far at least) as falling within the remit of the Care Act and Guidance, the demands of the statutory duties under the Care Act are now unclear. In light of severe ongoing challenges to social care in terms of funding, staffing and systemic issues, what constitutes a breach of statutory duty under the Care Act has become an opaque question. If reductions and stresses to provision of home care, closure of day centres, not giving written records of assessments, lack of choice for residential care, movement of assessments and services from in-person to on-line and reductions in follow-up, could all happen without breaching the Care Act, what is it that the law requires local authorities to do when their resources are stretched? What is the argument for reinstatement? Stresses on local authority provision of social care are well documented even without the pandemic and may provide cogent reasons for derogations from care. By not recognising past potential statutory breaches, the future strength of statutory duties under the Care Act has arguably been permanently undermined.

> **There was a perception that social care was seen as not valued and receiving less investment than health**

Legislative intention was to provide potential mechanisms by which easements might have supported local authorities unable to provide care and support in law or practice, and to provide transparency and accountability to the public (see *The Care Act Easements: Guidance for Local Authorities* in Appendix 1). It is not possible to say what the effects might have been if the easements had lasted longer, or if legal advice had prevailed to invoke easements because of the de facto withdrawal of services and reduction of provision. It is possible that differences in experiences would have emerged over time for service users as between easement and non-easement areas, or that additional support and resources might have been directed to easement areas to alleviate pressures, or that other consequences would have prevailed. In the event, none of these things happened.

Local authority resources are looking increasingly critical

Local authority resources, especially staffing levels, are looking increasingly critical, and some suggest they are in a worse position than in the first year of the pandemic. If the pandemic conditions allowed such derogations from usual care without breaching Care Act duties, then arguably such mitigations can continue in the circumstances now prevailing in many areas. There are critical stresses in carer support and provision.

By the time of the fieldwork with local authorities in this study, in mid to late 2021, the easement legislation had expired, yet all local authorities were reporting a surge in demand and pressures on staffing levels, receiving higher numbers and more complex referrals, and pressures on home care providers with staff shortages and increased sickness absence. This was particularly so in late 2021 as the Omicron variant struck. The stress was palpable. Both PSW/SLs and carers reported significant deterioration in people living with dementia at home. In some cases, local authorities were having to provide 24-hour support at home at high financial cost because of pressures on residential care, and PSW/SLs feared increasing numbers of carer breakdowns due to the unsustainability of the resilience and resourcefulness that had got people through the first year of the pandemic.

There was a very strong message that local authorities were seeing significant burnout in the workforce. By mid to late 2021 when the PSW/SL interviews took place, the social care workforce was perceived to be “leaving in droves”, vacancies were impossible to fill, and the emotional toll of the pandemic on staff was perceived to be significant. Demand for services had been relentless and with the Omicron variant emerging in late 2021, it all looked to be far from over. Many local authority social care front-line staff were working from home in unsatisfactory conditions in shared accommodation with little space. They were unable to separate work from home with no escape from the emotional toll that many cases involving social workers entail, as well as dealing with the impact of high rates of death on their service users. Staff lacked in person peer support, and PSW/SLs talked of being on an almost war-like footing. Morale was extremely low, with low salaries, media pressure, no thanks or recognition, and a lack of appreciation and respect for the social care workforce. Real concerns for the future of social care were expressed by almost all respondents.

By this time easements were no longer legally available to local authorities, having expired in July 2021. One PSW/SL interviewed in late 2021 reflected that staffing difficulties and recruitment problems were such that the easements might well be helpful then.

> **There are critical stresses in carer support and provision**

Conclusions

Carers have suffered greatly in the pandemic

Easements per se, for the reasons given above, had little impact on the experiences of older carers of family members living with dementia at home. The easements were short-lived (in some cases very short-lived), they do not appear to have resulted in substantively different behaviours as between local authorities other than a desire to be more transparent in their decision-making, and carers were unaware of them as such. From a carer perspective, there was no clear discernible difference in either the carer interviews or survey between easement and non-easement local authorities. But the pandemic itself and the ways that local authorities and allied providers responded to it across the country by reducing services and support, had enormous impact on the mental and physical health, and social wellbeing, of older caregivers. Carers seem unprotected with few options. They are dealing with an ambiguous legal situation and widespread stress and burden.

This carer group was commonly invisible and hidden to most local authorities because many were self-funding, seen as coping together, and/or often did not even identify themselves as 'carers'. They generally only came to the attention of local authorities when at crisis point. They have faced extreme challenges during the pandemic such as the withdrawal of services without appropriate alternatives, high risk of illness and death, and have often found themselves isolated without help with profound impacts on health and wellbeing. Many have been unable to secure good quality care and support. Whilst alternative provisions were sometimes offered, such as online groups or sessions or activity packs, these were often unsuitable because of the difficulties faced with engaging with this type of provision and were in reality, not really alternatives at all. There was no redress for issues of poor-quality care, with carers often attempting to cope with inconsistency of homecare workers, inappropriate or unreliable timing of visits, people not turning up, and at the start of the pandemic particularly, multiple workers visiting with limited access to PPE, which ultimately they felt compelled to decline.

The context of the pandemic contributed to and exacerbated these issues due to the additional stresses placed on an already stretched social care workforce, but these care arrangements also engendered increased risks of covid infection and death for those in receipt of home care.[42] There seems to have been no solution to the problems of carers needing a period of respite care, even in the face of acknowledged deteriorating physical and mental health of people living with dementia in the community. The pandemic led to increased hidden demand for assessment and support that was not met.

The easement policy was not a plan to meet the needs of carers, but rather a plan to provide a legal framework of protection of local authorities when carers needs could manifestly not be met from existing resources. The evidence from this study suggests a great burden of unmet need among carers.

The easement policy and legislation never worked as intended

This research has highlighted that many local authorities faced difficulties around the lack of clarity in the Care Act and ascertaining what their duties actually are, and what alternative provision can be considered reasonably to meet statutory duties. This resulted in seemingly diametrically opposed decisions being made by local authorities regarding whether they were complying with their duties under the Care Act and whether easements were necessary. These difficulties were further exacerbated by the negative narrative that surrounded the easements, even though those local authorities who enacted easements believed that by doing so, they were being honest and transparent and did so for what they considered to be ethical and the right reasons. In the context of the very negative discourse and attention around easements, and the conflicting legal advice given, many local authorities did not take such action.

Funding, resourcing, and cultural challenges for local authorities were manifest

Many PSW/SLs reported how the pandemic had highlighted the division in funding and recognition between the health service (NHS) and social care, with social care perceived as the poorer relation. This was accentuated by the recognition health received throughout the pandemic for making tough decisions and actions (including for example, clapping for the NHS), and the clear dichotomy that whilst health could re-prioritise services to deal with the pandemic without any political criticism or need for legal action, the local authorities had to enact the legal easements to do so, with wide criticism.

There is an irony in that whilst the final local authority ended its easement phase on 6 July 2020, and easements were no longer available by 16 July 2021, by mid to late 2021, local authorities were facing higher levels of demand than they had ever faced in the first few months of the pandemic (where carers had understandably cancelled care and were often assisted by family members on furlough). This increase in demand combined with a shrinking workforce for both social work and home care means that the risk of not being able to comply with Care Act duties (and the consequent need for easements) had heightened.

Limitations

There are a number of important limitations to this study. This was not case study research of either particular local authorities or of individual cases, and we recognise that any potential breach of Care Act statutory duties could only be determined on a case-by-case basis. While we present widespread and consistent evidence of what happened during the pandemic across the country according to the respondents to the study, the data also reveals variation with better and worse support for individuals. Importantly, the study interviewed individuals in positions of social work leadership from twenty local authorities, out of 151, and this research can therefore do no more than suggest that consistent findings from these 20 local authorities suggest a national pattern of consistent mitigations for pandemic circumstances. In terms of the survey, since this was not a random sample of carers, it is feasible that those with worse mental health outcomes from the pandemic are disproportionately represented in survey responses, if they were more likely to agree to take part in the research. Even if this is so and we cannot assess population prevalence, the survey confirms interview data revealing prevalent severe impacts of support deficits during the pandemic, in the face of high levels of need.

Implications

The category of aged 70+ co-resident carers has been very substantially impacted by the pandemic. The policy need is to consider how this rapidly increasing demographic group needs to be identified before any such future event, should similar events occur, and then how the needs identified in this study could be appropriately met, even in pandemic circumstances. Consideration needs to be given to resource provision for local authorities, so that if day centres, respite, home care, etc. need to close or reduce then real alternatives are provided which meet the needs of carers and the people they support. How to ensure safe home care during a pandemic that does not present unacceptable risk of disease and maintains sufficient quality of provision is an important question, as is the need to provide more acceptable forms of respite care that do not risk the separation and isolation from family carers that prevailed. Better practical, logistical and mental health support for carers seems urgently needed. Carers need to be at the centre of these discussions.

Care pathways after a dementia diagnosis are problematic with little integration between medical pathways and holistic care and support for carers. Attention also needs to be given to the diminishing workforce in social work, where individuals are retiring, often earlier than planned, many are leaving because of the conditions of work, and the difficulties currently being faced in their replacement. The low pay and poor working conditions (including zero-hour contracts) for home care workers also needs to be addressed to stop the mass exodus of home care workers. How to protect and preserve the social care workforce during and after a pandemic seems a vital question.

Finally, and although it is acknowledged that the Coronavirus Act was enacted very quickly, proper consideration needs to be given to the purpose of provisions such as easements and for a dialogue to be opened with the health system, local authorities, lobby groups, charities, and carers to consider how to respond in the future – legally, practically, and in terms of resourcing – in a way that better meets carers' needs, and those of the family members they support behind closed doors.

> **There are stark differences between the treatment of rationing of healthcare, on the one hand, and social care, on the other, during the pandemic**

Even though the option to seek easements expired in July 2021, understanding what happened during and beyond this unique period and what the consequences have been for local authorities remains crucially important for several reasons:

- the option to invoke Care Act easements has revealed ambiguities in legal thinking about what the statutory duties and Guidance mean in practice and, in crisis circumstances, what it takes to fulfil these duties, and what the consequences might be of a breach of duty;
- there are stark differences between the treatment of rationing of healthcare, on the one hand, and social care, on the other, during the pandemic, which raises questions for future emergency scenarios;
- the research uncovers a picture of family carers behind closed doors, already struggling prior to the pandemic with insufficient support at home, stretched to or beyond breaking point;
- the emergency systems implemented to support both local authorities and carers were fraught with difficulties, suggesting that renewed thinking is needed for future Covid waves or pandemics;
- the difficulties during the pandemic were overlayed on a home care system already under extreme pressure, with multiple challenges in providing adequate support to this vital group of carers;
- many older carers have suffered greatly in the pandemic revealing a class of people given little priority and inadequate support.

Further research

This research has revealed some important gaps in knowledge and understanding from socio-legal perspectives that seem important for future policy.

- Understanding care deficits for older people from multiple perspectives; how quality of home care is understood by funders and recipients; how self-funders and local authorities respectively conceptualise and meet needs; how carers respond to a situation where they perceive care to be insufficient or poor quality.

The perceived quality of home care and residential respite lay at the heart of many dilemmas for carers during the pandemic, presented problems of governance and control for local authorities, and as reported in this research remains an important challenge for care providers. Family carers are reluctant to raise issues or complain as this is fraught with risks for them (usually considered an important regulatory mechanism), and appropriate levers for improving or maintaining care quality to the satisfaction of caregivers seemed opaque. The barriers to raising issues in the current system are not well understood. These are important things to better understand to improve mechanisms of regulation and care quality. This in turn raises important research questions about how self-funders and local authorities respectively conceptualise and meet needs, how this works at the transition between self-funding and eligibility for local authority care, and whether it is ethically and legally appropriate for different standards to apply.

- how thresholds of "reasonable provision" under the Care Act are interpreted, and how these relate to needs and expectations from older carers

At the heart of this report is a lack of clarity around the meaning and interpretation of statutory duties under the Care Act, particularly when resources are stretched. This issue has not been resolved, and whether changes to assessment and provision in the face of the pandemic remained lawful is important for future practice. There are particularly important questions about the situation where care or support was offered but was considered too dangerous or of insufficient quality to meet needs by potential recipients; the limits of local authority statutory duties to assess and provide care remain unclear. This also has implications for understanding the role that complaints as a mechanism are or ought to be making in the governance of care quality.

- Moral distress and emotional dissonance experienced by the social care workforce in and following the pandemic – implications for workforce management and practice when meeting legal obligations is in conflict with doing good social work

The final research questions emerge from the way the easements were legislated. The easement policy was not a plan to meet the needs of carers, but rather a plan to provide a legal framework of protection of local authorities when carers needs could manifestly not be met from existing resources. As noted above, the evidence from this study suggests a great burden of unmet need among carers, but it also revealed substantial stresses for those in leadership roles in social work who took derogations from usual care extremely seriously. What the implications are for the workforce in terms of moral distress and emotional dissonance when meeting legal obligations is in conflict with doing good social work remains an unresearched, yet vital, question.

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Additional resources

https://www.opfpru.nihr.ac.uk/our-research/projects/the-impact-of-care-act-easements/

Presentation slides: Emerging findings to DHSC_ November 2021
(PDF)

Research with family carers of people living with dementia: recruiting during the pandemic
13th November 2021
(Ageing Issues / British Society of Gerontology Blog)

Teasing the easing of the Care Act 2014: Transparent legal protection or hidden unmet need?
21st January 2022
(Ageing Issues / British Society of Gerontology Blog)

Carers' Rights Seminar 28th January 2022
(YouTube)

Impact of Care Easements Webinar video
2nd March 2022
(YouTube)

Impact of Care Easements Webinar Slides
2nd March 2022
(PDF)

Care Act duties and COVID-19: Reflections on the rationing of social care
Home Care Research Forum Webinar Slides 18th May 2022 (PDF)

Older carers and their spouses living at home with dementia: a relational approach to understanding responses to service disengagement during the pandemic
Slides presented at the British Society of Gerontology Annual Conference on 7th July 2022

TIDE - Together In Dementia Everyday - Law for Dementia Carers (L4DC) Covid-19 Report (2021)

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