NIHR | Policy Research Unit
Older People and Frailty

The impact of Care Act Easements on co-resident carers over 70 supporting partners living at home with dementia

NIHR OPF PRU: The impact of Care Act Easements - lessons from the pandemic

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Project team: Professor Debora Price, Dr. Philip Drake, Neil Allen & Dr. Jayne Astbury

University of Manchester

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MANCHESTER 1824
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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

Authors: Professor Debora Price, Dr. Philip Drake, Neil Allen, Dr. Jayne Astbury
PPIE Advisory Group: Kay George, Mike Keoghan, Elizabeth Marsden, John Riley, Paul Stokes

With thanks to:

- The men and women, all family caregivers, who participated in this research, and to the Principal Social Workers, Safeguarding Leads and others in leadership roles in local authorities who agreed to be interviewed for this project.
- Our advisory board of older carers with spouses living at home with dementia, our project partners Together in Dementia Everyday (tide) and Making Space; and also Carers UK, Alzheimer’s Society, ADASS and the regional ADASS networks, and the many professional and carer organisations and NHS sites that helped us to recruit for the interviews and the survey. Special thanks to Join Dementia Research and the NIHR Clinical Research Networks.
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What are ‘easements’?

The Coronavirus Act 2020 included the unprecedented power for local authorities to temporarily suspend the majority of their adult social care duties required under the Care Act 2014. These suspensions were known as “easements”

Eight local authorities enacted Stage 3 or Stage 4 easements in April 2020:

- Middlesbrough [ended 22 April 2020]
- Sunderland [ended by 18 May 2020]
- Birmingham [ended by 18 May 2020]
- Staffordshire [ended by 26 May 2020]
- Coventry [ended by 1 June 2020]
- Warwickshire [ended by 1 June 2020]
- Derbyshire (Stage 4) [ended by 9 June 2020]
- Solihull (Stage 4) [ended by 6 July 2020]

Project Overview

Primary Objectives

- To investigate the impact of easements on this group of carers and those responsible for safeguarding within local authorities

Secondary Objectives

- Document impact of Care Act easements and reinstatement of statutory duties
- Compare and contrast experiences in Local Authority areas with easements and those without
- Understand challenges and dilemmas for those with safeguarding responsibilities
- Understand and document urgent challenges for carers and local authorities

Workstreams: April 2021 to July 2022

- 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 national survey of caregivers who were supporting a family member living with dementia at home (n=604 full responses).
- Legal analysis of the operation of the Care Act

Research findings: Carers

- Carers and the family member they were caring for experienced a significant reduction in available care and support
- Similar across all local authorities regardless of easement status
- Low carer wellbeing

In-home care stopped or reduced

- Few respondents reported that the local authority had initiated a reduction in existing homecare visits
- However, several carers reported making their own decision to temporarily suspend, delay, or end support from homecare
- Decisions based on perceived risks of Covid from homecare workers
- Existing challenges increasingly problematic in context of Covid: inconsistency of homecare workers, timing of visits, concerns regarding lack of PPE
- Family carers stepping in to meet resulting care deficit (furlough)
- For carers who felt unable to reduce homecare involvement the risks of Covid caused significant anxiety

Day centres, day care & in-person support groups closed

- All interviewees reported that day centres/day care & in-person support groups suspended
- Carers stressed crucial value of day services for both themselves and their partner

> She went to a day centre, you know, for five hours. And that was just a release valve to me. Just getting five hours was like two weeks. As soon as I'd drop her off, it was a weight of your shoulders. (Int 39, male carer, aged 76, easement)

- Many carers believed that their partners experienced accelerated cognitive decline due to reduced access to social interaction and activities provided by day services

Alternative provision: online

- Many carers felt that the online alternatives did not meet the needs met by the previously face to face service
- Carers reported that PLWD often found it difficult or were unable to participate in online groups.
- Some carers felt that supporting their partner to access online groups added to their caring responsibilities rather than providing respite
- *Out of 100 survey respondents offered an online alternative to a previously face to face provision, 81% reported that the experience was worse for one or other or both themselves and the person they cared for. More than half (52%) reported it was worse for both*
- Online carers support groups evaluated positively & felt to be more accessible by some carers but this was not universal

Residential respite care

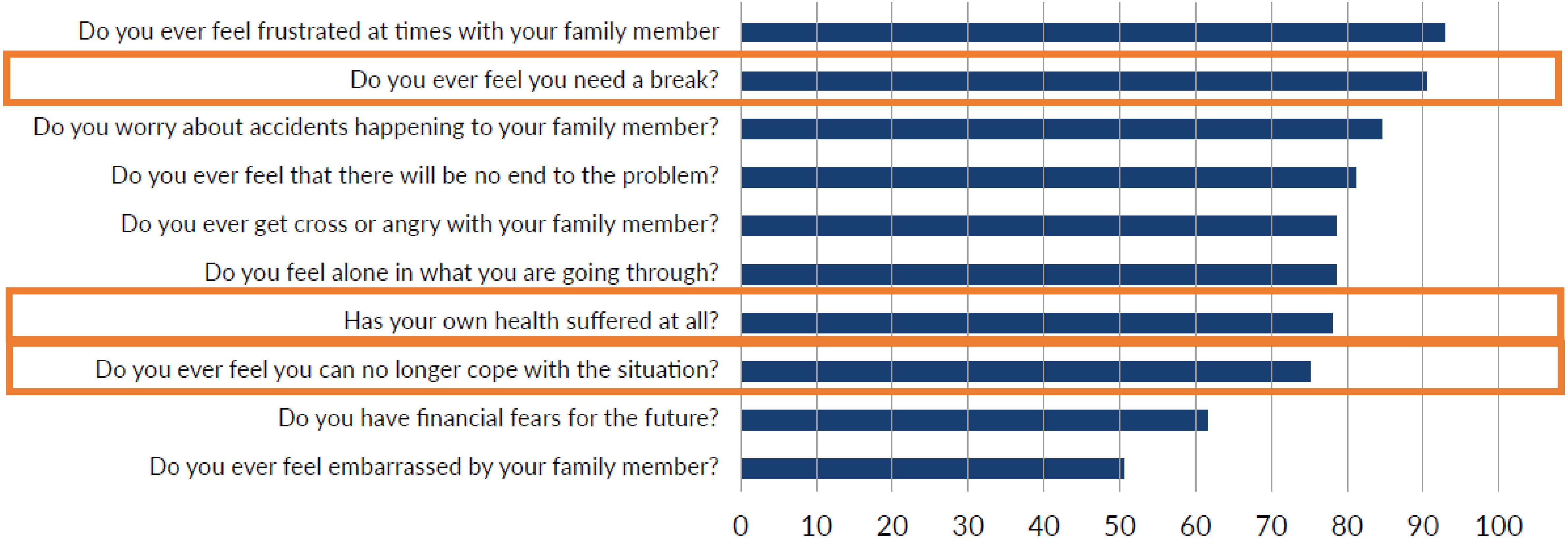
- Availability of respite care initially reduced
- Several carers reported declining respite due to concerns regarding risks of Covid, restricted visiting, isolation & potential deterioration

> 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. (Int 3: Female carer, aged 73, easement)

Ongoing reduced access to formal support for people in receipt of formal service before the pandemic: receipt of formal services before pandemic and now					***total***
Source: Carer Survey Table 3, page 24, final report					
Row percentages					
	Now no support	**Less support**	**The same level of support**	**More support**	
Social worker	52%	15%	18%	15%	100%
GP or community health services	30%	19%	29%	22%	100%
Befriending or visiting service	55%	17%	17%	11%	100%
Sitting service	43%	14%	24%	18%	100%
Respite days in a residential home	89%	11%	-	-	100%
Day centre days	48%	19%	17%	16%	100%

Survey measures of carer wellbeing & mental health (1)

Source: Carer Survey Figure 3, page 26 Final Report: Relatives Stress Scale questions



Survey measures of carer wellbeing & mental health (2):

Mental health & wellbeing: results from carer survey, Table 4, pages 26 – 27

	Survey respondents, caregivers supporting people living with dementia at home through the pandemic	English Longitudinal Study of Ageing COVID sub-study, Wave 1 comparison, 50+ population
High loneliness	57%	23%
High anxiety (clinical investigation advised)	37%	9%
Elevated depressive symptoms (clinical investigation indicated)	66%	22%

	Survey respondents	
	Co-resident	Lives elsewhere
High loneliness	62%	48%
High anxiety (clinical investigation advised)	40%	33%
Elevated depressive symptoms (clinical investigation indicated)	71%	59%

Inequalities in access to support

- Many carers highlighted vital support from family, friends and neighbours.
- Carers hubs, charities, carers organisations
- Existing relationship with named person or service that could be contacted for support and advice

> 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 I can turn to and say “Well ,I know I can contact them” or “It’ll be easy to get help from…” (Int 16: female carer, aged 74, non-easement)

- Impact of social, financial, and environmental factors

‘Hidden Carers’

- Difficulty in identifying our category of carers.
- Spousal carers often do not identify with the word “carer” rendering a mismatch between language and need
- Perceived stoicism in older generations, and cultural stigma around the symptoms of dementia
- Some local authorities sought to actively identify carers through mental health services, Admiral nurses and employing carer support workers
- Numbers coming to attention though dipped in the pandemic
- Many carers remained unknown and often did not come to the attention of the local authority until crisis point -*“they only knew the ones they knew”*

Service-users declining services & furlough

- Home care stopped or refused, almost always at the request of the couple.
- Interaction (unintended) with the furlough scheme released family members for care.
- Unexpected reduced demand provided some ‘slack in the system’.
- Letter confirming care had been withdrawn at the service users request & requesting the service user to get back in touch, if any problems.
- Few instances of further regular follow up (crisis point?).

Care Act Assessment Delivery

- Move from ‘in person’ to remote assessments (i.e. telephone calls, video calls, MS Teams, WhatsApp, and Facetime) cf Mental Health Act assessments.
- Multiple challenges:
  - the technology itself;
  - for people with cognitive difficulties and sight and hearing impairments;
  - the loss of the ability to see or hear what the situation was in the home; and
  - intimacy in discussions.
- A clear aspiration that face-to-face assessments resumed, particularly for this category of carers.

Interpretation of the easement legislation

- Easements were differentially implemented, & soon revoked
- Some of the reasons for easements:
  - the actual or anticipated diminishing capacity of the workforce and the need to reprioritise services (most common);
  - closure of day centres;
  - inability to send written communications by post;
  - inability to offer choice of care home providers or preferred accommodation; &
  - inability to offer annual reviews.
- Many of these issues were common across all the local authorities in this study, in both easement and non-easement areas
- Main difference was in the legal advice that was received
- Professional Networks i.e. ADASS, PSW & contingency exercises influential in decision making.

Responses to the easements

- No consequences, either political, legal, or regulatory, for local authorities that did not enact easements
- Stressful consequences for the local authorities that did i.e. attacks from media, public pressure and legal threats
- Easement local authorities believed they were doing the right thing, the moral thing, acting transparently & in the spirit of the legislation (shocked and surprised others had not followed)
- Non-easement local authorities suggested easement local authorities had ‘jumped too quickly’
- Easement local authorities felt more could have been done nationally to protect them

Differential treatment of Health (NHS)

- Social care seen as less valued, receiving less investment & little support
- The health service able to make rationing decisions without statutory intervention or the same political and public pressure
- Health decisions impacting negatively i.e. discharging people to free up beds
- No recognition how, with proper resources and investment, social care could do early preventative work to save future health costs.
- Perceived prioritisation of health to the detriment of social care

Increasingly critical staffing resources

- Exodus of home care staff to the retail, leisure and hospitality sectors.
- Social work staff having to work from home during the pandemic with lack of ‘in person’ support
- Significant burnout in the workforce
- Social care workforce *“leaving in droves”* and major difficulties in recruitment
- In a worse position in late 2021, than in the first year of the pandemic?
- Critical stresses in carer support and provision
- Could mitigations and derogations from usual care continue in the circumstances now prevailing?

How did local authorities act lawfully when ….

- 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)?
- Whilst 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))?


Care Quality Commission

The state of health care and adult social care in England 2021/22

State of Care

HC 724

State of Care 2021/22

- c.500,000 people may be waiting either for an adult social care assessment, for care or a direct payment to begin, or for a review of their care.
- 61% local authorities said they were having to prioritise assessments and were only able to respond to people where abuse or neglect was highlighted, for hospital discharge or after a temporary period of residential care to support recovery and reablement.
- In the first 3 months of 2022, 2.2 million hours of homecare could not be delivered because of insufficient workforce capacity, leading to unmet needs.
- Nuffield Trust report (Dec 2021): reduction in staff "*is fuelling an invisible care crisis in people's own homes with many unable to access the care they need, increasing care burdens on unpaid carers and impacting hospital discharges*".

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Newcastle University

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Implications and Conclusions/1

- Carers have suffered greatly in the pandemic
- The easement legislation created incentives to challenge the invocation of easements rather than deficits in care
- Legal advice to local authorities varied widely
  - Our research suggests that given the experiences of carers and the legislative framework, from a legal perspective easements ought to have been invoked much more widely (but cf the rationing of healthcare which required no such declaration)
- Were statutory duties met? Are statutory duties now being met?
  - Calls into question, from whose perspective
  - What are the consequences of not meeting statutory duties?
  - Are these duties without de facto remedy?

Implications and Conclusions/2

- The legislative logic (plan) was for the most extreme care and life-saving care needs to be prioritised, and protection given to local authorities who could not do all
- Unclear what the longer term plan for unmet care needs in a prolonged pandemic situation was
  - Unintentionally saved by the furlough scheme, but furlough may not be available in future crises
- Problems in the proper resourcing, structure and workforce support for social care
- The undermining of the rule of law has implications for the integrity of the Care Act, where the ability to meet strict statutory duties is insufficiently resourced/supported
- There are few to no practically accessible and effective remedies for perceived poor quality homecare

Thank you:
Q&A

- debora.price@manchester.ac.uk
- philip.drake@manchester.ac.uk
- neil.allen@manchester.ac.uk
- jayne.astbury@manchester.ac.uk

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


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