LAW FOR DEMENTIA CARERS PROJECT

COVID-19 SUMMARY REPORT

What is Law for Dementia Carers?

L4DC is a partnership project between the Life Story Network/tide and Making Space, funded by The Legal Education Foundation. Working together with support from The University of Manchester's Justice Hub, the project aims to raise the awareness and knowledge of the legal rights of carers of people with dementia.

Why we focused on Covid-19?

Following the onset of the Coronavirus pandemic, the subsequent lockdown restrictions and the introduction of emergency legislation, the project was re-focused on assessing the impact of the Coronavirus Act 2020, the Care Act easements, and the impact on carers, in the knowledge that their caring responsibilities were likely to increase. This would provide evidence to submit to the UK Government's review of the legislation after six months.

What did we want to find out?

- the experiences of carers of people with dementia across the UK of the Covid-19 legislation and other legal matters during the pandemic
- the extent of knowledge of carers about their legal and human rights
- how Greater Manchester Health & Social Care Partnership implemented the legislation in respect of carers of people with dementia.

How did we do this?

- Produced an easy read guide: 'Easing the Care Act'
- Hosted two webinars: one referencing England in particular and one specific to Scottish legislation, to provide legal information relating to dementia and to covid-19 legislation
- A survey of carers about legal issues, with follow up in-depth interviews of a small sample
- A survey of the Greater Manchester Health & Social Care Partnership

These activities included the following people, most of which were carers or former carers:

- 149 in the first legal webinar
- 74 in the Life Changes Trust Scotland webinar
- 191 in the UK-wide survey

What did we find out?

Only eight local authorities in England invoked the easements of their statutory responsibilities allowed under the Coronavirus Act 2020.

There was a lack of transparency about decision-making processes and the impact of the changes and some local authorities changed their practices without invoking the legislation.

Only **18%** of carers surveyed said there had been no change in their caring responsibilities since March 2020, with **58%** saying there had been a lot of changes. Some reasons included:

- Deterioration in the health and well-being of the person cared for:
  "Major changes to circumstances. The lack of being able to take the person you care for out even just for a small walk has had a major effect on the person I care for. Health has deteriorated drastically plus my own health and well-being has drastically taken a downward turn"
- Health and social care services, including community clubs and activities, were unavailable or much reduced:
  "I have taken on the role of day to day care of my mother since March as the care package was put on hold. Other services including OT was put on hold, even though my mother left hospital just before lock down with hip replacement. I have needed to escalate as emergency for any additional services."
- Some carers chose to safeguard the cared for from the virus by cancelling support services
- Carers of people in care homes found their caring roles completely curtailed

When lockdown commenced, **50%** of carers did not have a carer's assessment and **12%** said it was not applicable; during the pandemic, **59%** had not requested an assessment, **7%** had done so and been refused and **34%** said it was not applicable. Feedback from carers suggests that:

- Not all carers are aware of their right to an assessment

- The Care Act easements were used as a reason not to undertake assessments by some local authorities, including by some authorities who had not formally invoked the easements:
- Carers' assessments are not always seen to be of value:
  "my carer's assessment amounts to nothing in terms of support"

At the time of the survey, **36%** of carers (or the people they were supporting) were receiving no support compared with **28%** in March 2020, indicating a shift from paid to unpaid care. These figures mask the number of cases where carers were still receiving support but significantly less, for example when day centres had closed. Some carers were told that the person they were looking after was a low priority for a needs assessment, because although they probably had eligible needs they would be above the threshold for financial support:

"The person that I care for has not had a needs assessment. I have now requested one and been told that there are definitely 'eligible needs' but as we are not entitled to any financial help I have been told that we would be 'low priority' and we are waiting for a social worker to be allocated."

This is incorrect: needs must be assessed before the financial eligibility criteria are applied.

58% of carers told us that they were not able to continue as a carer in the way they wanted to; for those not living in the same household as the person with dementia, this rose to **72%***.* This was particularly so for carers who lived a distance away:

"As I live 70 miles away I have been unable to travel to either of relatives with dementia. One is in a care home and one in extra care sheltered. Neither establishment has been proactive in supporting my relatives to keep in touch despite us providing iPads"

For those whose relative or friend lived in a care home the separation was especially difficult:

"Not allowed to visit. My husband wasn't eating and drinking. He has lost a lot of weight I feel he was pining for family. I feel I could have coaxed him to eat and drink"

Only **32%** of carers said they knew their legal rights and had access to information. Particular issues raised included:

- Confusion about how the health and social care system works and how to seek help:

"The information in the media, and largely what I have found online relates only to typical working families and essential workers. Anyone outside that seems to have been overlooked."

- Rules about financial assistance:
  "I'm a working carer on a minimal wage I'm not entitled to carer allowance as I earn 130 a week which is just a little over the entitlement for the cares allowance This is so unfair as I pay for my own experience to care for my mother who has Dementia I need financial help to support me as a carer for my mum"
- Feeling undervalued as a result of a lack of information
- Frustration that even when carers know their rights, these can be ignored or overruled by health and social care staff:
  "*There was a situation at ….. Hospital over my husband's care where I was told that POWER of ATTORNEY just simply didn't matter. They took him off, asked him thousands of questions which he couldn't answer so he began to make up the answers and this affected ... influenced the care they gave him .. or in this case DIDN'T give him. He was discharged with severe concussion, couldn't walk out of A and E, and was being sick ... and not making any sense to me. I had to take him back next morning because he was bleeding from his eye ... to find out that they had recorded the rubbish he had spoke even though he had dementia and recorded it as FACT. The second time they did allow me to stay with him as his representative. I know my legal rights and those of my husband were breached but did not know enough to stand my ground."*

42% of carers felt they had been treated with respect by the professionals with whom they came into contact. For those whose experiences were less positive, professional disregard was particularly evident in relation to 'Do not Resuscitate', Advanced Care Planning and decisions to withdraw care or treatment. Many carers spoke of a sense of abandonment and a lack of recognition for their role as experts in the care of the people with dementia they were looking after:

"I am recognised only as my husband's wife and no longer as the person who previously provided personal and emotional support. My visits are intermittent and at a distance. I am unable to comfort or touch on husband during these visits. There is a chaperone present, always to ensure the visiting guideline are not broken."

What are our recommendations?

1. Legislation and guidance should reinforce that the right to a **carer's assessment** has not changed as a result of the Covid-19 global pandemic. Systems should be in place to monitor that legislation and guidance are being implemented by local authorities.

2. Unpaid carers form the biggest dementia workforce and save the health and social care economy about £13.9bn per annum, even before any impact of the pandemic is taken into account. The care home sector needs clear guidance about how to work with unpaid carers and include them in the care of residents safely. The proposal to government from One Dementia Voice to enable unpaid **carers to be recognized as keyworkers** should be supported; this would enable carers to have contact with residents in a care home in a safe and managed way and give them access to Covid testing and PPE. The care home sector needs clarity about how to include unpaid carers.

3. Health and social care should automatically include **carers as equal partners in key decision-making** that affects the person with dementia's health and well-being. This should be accompanied by clear guidance to staff with monitoring arrangements in place to ensure decision making conforms to this standard. Staff should be reminded that carers have a legal right to be involved, for example, when they are acting under a Lasting Power of Attorney.

4. The rules around eligibility for the **Carers Allowance** should be revised on a temporary basis to reflect the current situation and the potential for further waves of the virus.

5. **Information should be publicly accessible and transparent**, for example concerning Care Act easements. Front line health and social care staff need to have an awareness of legal issues in relation to their role and those of carers and people with dementia.

6. Local authorities and their front line staff should exercise **creativity** about meeting needs in partnership with carers and the person with dementia to provide **alternative options for care and support** where possible.

7. The crucial role of **community support** activities and their ability to diversify to provide a range of approaches in a changing environment should be recognized and supported by health and social care commissioners.