



Lockdown Impact on Dementia Care in the Community

SURVEY SUMMARY

August 17th, 2020

Unpaid dementia carers look after about 600,000 people with dementia who live in their own homes in the UK, saving the state billions of pounds per year. Without these 'informal' carers, many people with dementia would face long-term care admission against their wishes, and greater costs of care would fall to the taxpayer. Our survey, completed by 75 dementia carers, describes their experience of the UK lockdown (March-July, 2020). Findings suggest that national policy and local planning need to offer carers more help if/when another lockdown happens. [The report](#) presents the detailed survey results and recommends six strategies for improving the lot of dementia carers.

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

Lockdown had negative effects on carers' wellbeing. It deprived them of the support and activities they need to look after individuals with dementia. **National policy and lockdown strategy should:**

1. Recognise carers as key workers.
2. Treat the caring dyad as a single person

for shopping, forming social bubbles and similar.

3. Give dementia carers the help they need to continue under lockdown.

Lockdown caused excess disability in people with dementia, who need responsive health care, social contact, exercise and cognitive stimulation to resist deteriorating with the disorder. **Commissioners and professional bodies should:**

4. Find ways to deliver health services to people with dementia in their own homes, particularly chiropody, audiology, GP consultations and dentistry.

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

Nothing had been put in place by his social worker as to what would happen to him if I, as his sole carer, became ill with coronavirus.

Local authorities and community organisers should:

5. Maintain a register of dementia carers who may need support to continue caring under lockdown conditions.
6. Provide targeted care management for these households to prevent carer breakdown.

With appropriate virus control measures where necessary, this **care management should include:**

- a. Personalised activity plans and materials for people with dementia to use if restricted to home.
- b. Home companionship, home care and residential respite care, treated as essential services.
- c. Proactive telephone support and expert counselling where needed.
- d. Face to face visits to monitor the caring situation and reassure some carers.
- e. Access to expert dementia advice and information about obtaining practical help for personal care and home maintenance.

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

We have been badly let down and some of us left to die, or wanting to die. Some of us (at times me) would have welcomed Covid-19.

Further information

The full report can be downloaded here: www.thebeestonstudio.uk/lockdown-survey

Declaration of interests

This survey and its dissemination were funded by the National Lottery/Arts Council England through a Covid-19 emergency response fund grant (ORGR00242083) made to The Studio at Padge Road (www.thebeestonstudio.org). Justine Schneider who designed and analysed the survey is one of three unpaid directors of The Studio and received no remuneration for this work.