

Imagine Artsdem Broxtowe CIC – Written Evidence (LBC0075)

SUPPORTING DEMENTIA CARERS IN A POST-COVID FUTURE

We are a small non-profit that provided arts-led daycare for people with dementia before lockdown. We kept in touch with our clients over the months of lockdown, and were given a small grant from the Arts Council to survey their experiences.

Two-thirds of the 800,000 people with dementia in the UK live in their own homes, supported by family and friends. Most people with dementia lead a precariously-balanced existence, relying on a spouse or child to manage their care, ensure their safety and provide activities. Going out to dementia cafes, shopping and socialising supply vital cognitive stimulation and social support. When older people were required to stay home all this was taken away. Consequently looking after a person with dementia under lockdown has been a devastatingly lonely time for carers, while the individuals with a diagnosis have deteriorated through lack of stimulation. In short, the lockdown has caused excess and avoidable harm to this group of people. The needs of these dyads are different from individuals and couples who are not coping with dementia. It's clear that dementia care in the community needs to be supported better in a post-Covid future. As evidence for this consultation we wanted to share the unedited comments from the first 37 dementia carers who completed our online survey. Full results and analysis will be published in September on our website: www.thebeestonstudio.uk

Dementia Carers Under Lockdown-Saved

23. In closing we invite you to tell us more about your experience of dementia care under lockdown. Remember, nothing you say will be reproduced in any way that could permit you to be identified. At the same time, if you reveal anything that suggests that you or anyone else is at risk, we reserve the right to alert the appropriate authorities

37Responses

ID	Name	Responses
		Test
		test
3	anonymous	We have had support from neighbours to help with shopping. We have a carer group who keep in touch and support each other via WhatsApp. But we miss face to face contact with friends and family
4	anonymous	Feelings of anxiety and worry for the future. Many people died in Mums care home. Information was scant at the start. No information on swabbing residents or staff was passed on to relatives by the home. I rang City Care Nottingham and spoke to nursing staff and infection control. They helped and contacted the care home. Things improved after this with regard to information. I felt sorry and worried for staff at the start of lockdown as they told us they were not given enough PPE. Mum was fine and didn't get Covid thankfully (so far)
5	anonymous	We have received support from family and friends only, offers of virtual support are not good for people with dementia, and sole carers so not have time for virtual support, it would have been nice to have a short phone call
6	anonymous	My husband has really missed going to the cinema, our singing group and going shopping and going out on trips and for a meal in Nottingham or locally. He was very upset to read that people with Dementia are more prone to the virus. My son has been shielding and has not been out for weeks and months -he's had phone appointments with a Consultant and GP, but he's still experiencing erratic absences and seizures.

ID Name	Responses
7 anonymous	Initial closure of local shops made it difficult, but neighbours provided help. Later most things are available locally but being sole Carer means that I have significant time constraints. With dementia worsening significantly Social Services have been excellent.
8 anonymous	It has been a real 'mixed bag' for us. Some very good experiences: friends and neighbours offers of help, lots of good telephone chats and texts, Zoom sessions. And some not so good experiences: shopping is stressful, it's boring and tedious and the days run together. We both had dental, chiropody and hair salon/barber appointments which have been cancelled. Repair jobs have not been able to be done.
9 anonymous	Very difficult, No respite, packing to move as well, no home help, care or Dementia concern or Befriend visitors who took him for walks, to cafe and did exercises with him regularly. Stressful as his falling means I would have to call an ambulance as I have osteoporosis and cannot lift him or he could fall on me.
11 anonymous	It has been very stressful my husband has ftd and is ocd with what he does daily since all his activities have closed he can't understand social distancing and refuses to queue any where it's a nightmare. Now government have announced social bubble but not for us who are like single parents to a toddler. I have ignored this as it is common sense and I am in a bubble with my sons family who both work from home. My husband is safer going there than trying to socially distance outside the house. Boris Johnson should be ashamed his rationale was that single people feel isolated from their loved ones well I wish I was single and could go out when ever I like shop when I like meet friends outside when I like. I am using my common sense
12 anonymous	My wife has got progressively worse over the lockdown period. Both her speech has deteriorated and her behaviour. All our groups / support ceased immediately and there has been no replacement other than a couple of phone calls. I do not believe enough is available remotely and in an easy to access way. I do not know if she will recover or if this decline is permanent. My wife has continence issues and so we can't travel unless public toilets are available. With them closing, trips to the park or gardens are not accessible for us. I am under increased pressure and there is limited support. My family are in touch regularly, we have a zoom call 3 times a week. One daughter lives locally and she does our shopping and has sat with my wife on a couple of occasions when I had to go out. I am very worried this lockdown has had a serious and irreversible impact on my wife.
13 anonymous	Mums pattern is now a full 72hrs of singing. It is lovely whilst a happy song but when she is anxious and has forgotten completely who we are and wants to go home or see her mum (shes 84), it is a long continuous lament. She sings all night through too. We have a camera to watch her at night as we just have to try to get some sleep but it lets us check shes ok. She doesn't realise it is her singing, and there is no way she can stop, and its obvious the noise upsets her too. She complains when her voice gets croaky which to be honest is not surprising. After 3/4 days she sleeps all day. Before lockdown we could take her out and it felt like we had some chance of normality - go for a coffee, meal, something. With no respite we are exhausted, emotionally and mentally.
14 anonymous	Those with dementia need FACE TO FACE interaction, especially as their speech declines. Safety first though!
15 anonymous	It has been very lonely and exhausting. GP only available by phone and unwilling to help when finally reached. We have managed but only because we will not let daddy be at risk, and sacrificed everything else to keep him safe.
16 anonymous	I sometimes feel overwhelmed by what I am doing - managing medication,

ID Name	Responses
	changing dressings and continence bags keeping an eye on his wellbeing as well as all the usual domestic staff. I am not medically trained and have had to pick things up as I go along and just hope I don't miss anything.
17 anonymous	Due to the risks posed to mum and carers I have reduced my visits to once a week for essential care. Prior to lockdown I'd visit at at least once or twice in the week. I asked the agency their COVID cleaning g routine and try and replicate this when I do my visit. My mum has deteriorated e.g. yesterday when the newsletter came from the memory cafe and we talked about her going she couldn't remember whereas it used to be one of the highlights of her week. She has become less independent as lockdown has progressed. .
18 anonymous	My mum broke her hip and was admitted to hospital at the beginning of the lockdown. When in hospital she got the coronavirus and was transferred to a coronavirus ward causing a lapse in her post op rehab. After 3 weeks in hospital she was moved to a care home for a temp stay. There she is isolated in her room with very little social contact or stimulation and I feel that these combined experiences have had a severe impact on her mental and physical health. Having said that, if she was still at home she (and I) would also be struggling with the lockdown restrictions as she likes to go out. In this respect I think that "the pill" is going to have an even worse impact than "the ill".
19 anonymous	The decline in both cognition and physical health since the beginning of lock down has been shockingly quick and we have had no face to face visits from any health care professionals apart from emergency ambulance call out twice. The stay in hospital without any carers or relatives for someone with advanced dementia is distressing to both the person and the family. My mum had a DNR put in place without anyone attempting to contact me about it from the hospital. I only found out from her discharge papers!
20 anonymous	simply cannot cope
21 anonymous	It's difficult to tell mum that her grandchildren cannot visit for her own safety. It's really hard when she forgets things so quickly and thinks that her friends are still going to the day centre, so why can't she?
22 anonymous	All the support I had in place for us both was suddenly taken away which was a frightening experience and I felt very isolated - the weekly telephone support calls I have received from our groups have been sustaining . I feel life has gone downhill for us both in lockdown and the uncertainty of how all our previous dementia support (which kept me going) will be able to be provided in the future is very concerning and a daunting prospect.
23 anonymous	Rang the dr as I was getting no sleep as my wife was continually getting up in the night .Halusinating. The Dr said he wound arrange for someone from the dementia team to come to see us but nobody ever came
24 anonymous	Lockdown has certainly affected my wife. She has become more clingy, probably as a result of losing her normal activities like her day centre, Singing for the Brain and Memory Cafe.
25 anonymous	It has been extremely hard during the last few months, battling with agencies to get support and medication for my mum. The Admiral Nurses have been a god send. My mum just didn't understand it all and it has been extremely mentally draining for us as careers.
26 anonymous	My wife has settled well probably due to the regimented days. We have walked regularly and more or less done the same every day. Before we were doing lots of things which now I see going to football ,cricket was too much as well as travelling. I think now this was unsettling for her. Its routine she needs.
27 anonymous	my husband has got much worse and I feel I am sinking under the pressure. most nights when I go to bed I pray not to wake up.
28 anonymous	We have benefitted from the routine .Rather than doing lots of things Eg

ID Name	Responses
	travelling,visiting friends and family.as well as watching football and cricket. We have really missed swimming and going to the pub.
29 anonymous	Due to no day centres open and various dementia groups not on ,I'm finding my husband has become very introverted and lost interest in things ,sadly .
30 anonymous	Thankfully dad is housebound so doesn't miss going out - I am very careful where I go and try not to go to too many different shops etc - in some ways I have been able to give more time to dad as I am furloughed at present but on the other hand I don't really have people to talk to so am bottling things up making my anxiety and stress worse
31 anonymous	the mental stress goes unnoticed by the world but it is an extremely real to the person suffering dementia they cannot understand any reasoning so feel the carer is deliberately keeping them in isolation not allowing them to go out or friends etc to come in to see them this tension builds up inside them until it becomes unbearable and the mind cracks, sadly they suffer an other loss of mental faculties this happened to my wife. Life is completely changed we all become much sadder ISOLATION is devastating much misunderstood has far reaching consequences
32 anonymous	Complete rollercoaster...with having falls being exposed to covid...finding out she has breast cancer again...it is incredibly hard trying to keep her safe. My emotions are at odds. I hope she dies soon but I dont want her to go.
34 anonymous	Anger with politicians- their on power trip in some US states- encouraging protesters an expected covid rates to fall thereby punishing senior with more lockdown
35 anonymous	Hard to explain places are closed and we need social distency
36 anonymous	Lonely for both.
37 anonymous	The Dementia group who we interact with, & the support they give, has been missed although through Zoom the carer's have still had the support collectively & individually if needed by follow up. Personal/physical interaction & not seeing/meeting people in the group has been very much missed by the both of us. Me for interaction with the other carer's & my husband seeing/meeting others with dementia.

5 August 2020