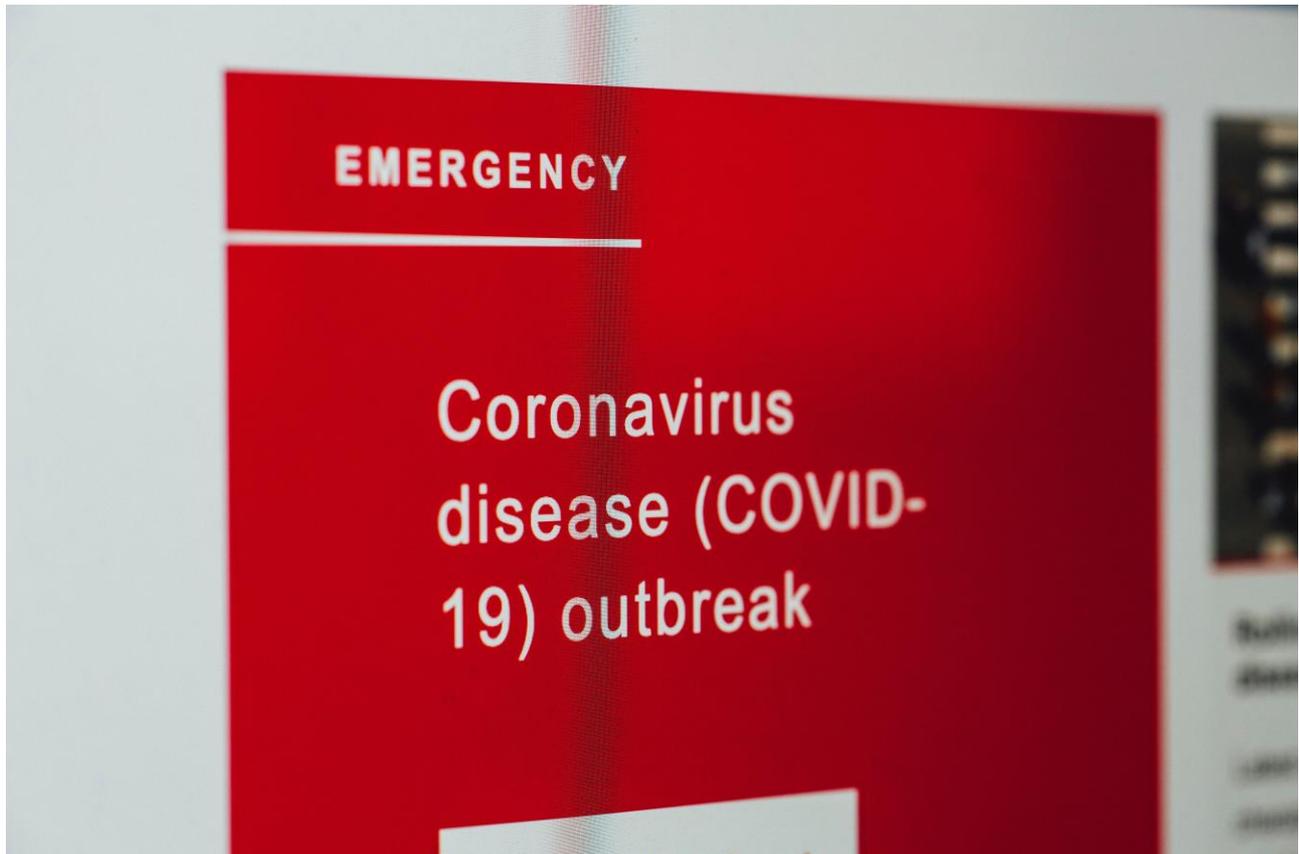


# Sibs

For brothers and sisters  
of disabled children and adults



## Coronavirus (Covid-19)

The impact on adult siblings who have a disabled brother or sister  
July 2020

Sibs is the UK charity for brothers and sisters of disabled children and adults  
Registered charity number 1145200. Limited company number 7834303.

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## Disclaimer

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## Facebook and Twitter Polls, May 2020

*"Coronavirus has made my situation as an adult sibling with a disabled brother or sister..."*

| Response         | Twitter | Facebook | TOTAL     |
|------------------|---------|----------|-----------|
| More challenging | 37      | 69       | 106 (91%) |
| Less challenging | 0       | 6        | 6 (5%)    |
| About the same   | 5       | n/a      | 5 (4%)    |
| TOTAL            | 42      | 75       | 117       |

Facebook limits responses to two options; Twitter limits responses to three. We encouraged further comments and feedback. We received one comment, on Facebook, which was:

*"Offering emotional support via the phone & Skype is hard especially when it goes wrong! Sometimes I've received 100s of messages a day. My sister just wants to go to see our parents, but can't and it's making her distressed."*

## Fiona – I feel sick with worry about what the future holds

Thinking about the impact of Covid on me and my family... I don't really know where to start. I am coping and we are coping because we have to. I feel at the minute that there will be a cost to this coping and I am worried about what this means for the future - for my brother's future, my family's future.

We are coping because we have a family member who is extremely clinically vulnerable and needs to be shielded. My brother needs 24 hour care (including through the night) due to complex medical needs. At a time when we had very little support pre-Covid, we now have even less. How does anyone make a decision to allow others into their bubble? Carers who have families and lives of their own - we can make the decision to shield to protect my brother, but we can't expect others to do the same.

As an adult sibling, I find myself at a stage in my life where I am determined to have just that (my own life). But it is so difficult to think about my own needs at a time when the needs of my brother and my family are hugely increased. My parents are not getting any younger and the needs of my brother are increasing. I really worry about for how long we can do this. What will happen after Covid? Will we get the care that we so desperately need? Or will we have to continually fight so that my brother can receive appropriate and dignified care?

Covid has increased anxiety levels in my family hugely. What will happen if my brother gets poorly and needs to go to hospital? What if one of us gets ill? How long can we cope without support? Will my brother be offered treatment if he needs it or will people not see past the disability? So many questions at a time of massive uncertainty and so few answers.

The biggest challenge for me at the moment is juggling. I'm working full-time and supporting my family and my brother at a time when I also feel quite lost in the uncertainty of the situation with Covid. I'm trying not to think too much about the 'what ifs' and just focus on getting through the present moment. I'm trying to make sure we can meet the needs of my brother and I'm trying to stay positive for him.

The thing that I would like people to know about being an adult sibling at the moment is that appearances can be deceptive. To outsiders, and my family, I am coping. I

work full-time and help to care for my brother every day. Inside however I feel sick, sick with worry about what the future holds. How long can I continue to keep all of the juggling balls in the air and make sure that my family survives this?

*All names have been changed.*

## Lucy – I had to lock myself in the garage to work and I could often hear my sister screaming in the house

The impact of Covid has been huge. Probably not in such an obvious way as other people, but in ways that have had a cumulative effect on my disabled sister, myself and our parents.

We look after her at home, after she was failed by five care homes. There was neglect, then neglect and misuse of medication, a fire that killed one resident, abuse which was never addressed, and a complicated relationship with the last care home and social services which was horrendously nasty and stressful. The care home hadn't managed to wash her hair in four weeks or give her a shower/bath in three weeks and social services thought this was acceptable and threatened us if we brought her home. In the end we brought her home for good and received an apology from the CEO of the care home company but not from social services, which has since made our relationship with them very fragile and tense.

We did not hear from social services when lockdown began. My parents, probably like many others, worry about rocking the boat and don't like to trouble people. So I would chase social services on social media and the phone until I finally got a response. It took almost two months, and it's always emotionally draining to fight for your parents as well as your sibling.

Our father is on the extremely vulnerable list, both parents are over-70, and my sister needs to shield for her own safety. She has a severe learning disability, low-functioning autism, very challenging behaviour. She bites objects when she's frustrated, angry or in pain. She spits her food out repeatedly throughout the day, asks for snacks and spits half of them out. It's exhausting to keep cleaning up numerous times a day.

It's also tiresome for us to fit our own meals around her. My father is diabetic and he's often dealing with her meltdown when he should be eating his meal because his blood sugar is low. I miss being able to eat a meal in peace - I often have to hide in a corner of the garden or even the garage to eat, otherwise she will want my food as well as hers. If she hears me talking to one of my parents when I try to share mealtime with them, she will get jealous and have a meltdown, so we tend to eat one at a time. I miss eating with company and I miss going out for coffee or a meal by myself.

She has lost her routine of going out every other day to a park or quiet cafe or museum or library. When she used to go out she would often touch objects (doors, tables, handles etc) and touch her mouth. It would be impossible to stop her from doing this now with the virus. She wouldn't wear a mask (or gloves, except in the winter). She doesn't understand anything about the virus or why she isn't going out, why we have no visitors, or why her whole family are at home all of the time. It's overwhelming everyone being at home all the time. Sometimes one of us will pretend to go out, but this doesn't always work - she's very perceptive and often knows when someone has just locked themselves away in a room. She will bite the door and have a meltdown until they "come home".

Her respite worker from the local day centre used to come over for a few hours twice a week. Often it wouldn't make a difference in terms of my sister's care, but I think my mother appreciated having another person to witness the burden of care. Sometimes the respite worker would take her out in her car with one of us, as my sister now needs two-to-one care. So now my sister hasn't seen her, or any other visitors, since the end of March. She will not distance from people so we can't have anyone visit, even in the garden. This has made her even more clingy than before. It's just been a tiny world of her home and garden (she rarely uses the garden) and her parents and sister.

We used to worry when she hadn't been out for a few days, that she would get into a new habit of not going out because of her autism and anxiety. Now it's been months. Even if we could take her safely out somewhere, it may be an ordeal to get her to come out. She is often screaming as she is told to get in a car for a hospital appointment or another appointment that we can't cancel just because she's in a bad mood.

Because of the heat, her bedroom window is often open but she has become increasingly sensitive to noise during lockdown. The neighbours have friends over and children and can be very noisy in their garden. Other people are using this time to have work done, e.g. roof extensions, skips delivered, and it is noisy a lot from 8am onwards. My sister gets very annoyed by the noise, but we can't stop it. She may be wondering why other people are going out but we aren't. For us, her family, it makes us feel more alone and uncared for. Other people seem to be enjoying themselves but we can't.

As the time goes on, we are more exhausted each day, emotionally and physically. It is hard to give her the routine she needs every day when we haven't had a break. We become irritable with each other and tired of supporting each other as well as her. We are sleep deprived because she doesn't sleep well and tires us out in the day and night.

I have had to give up my work as it involves emotional support phone calls to people who are sometimes very distressed - I had to lock myself in the garage to work and I could often hear my sister screaming in the house. I felt guilty about leaving my parents to cope with her when I was supporting someone else. I found it harder to work and suffered from burnout. Now I feel a loss of self-esteem and identity from not working. It is yet another way in which my life is very different from my friends'.

Although I feel especially lonely during this time, I often find it hard to speak to friends. One thing is the timing - the best time for me is early in the morning but most people don't want to/can't chat then. In the day and evening it's very hard with my sister so unpredictable. Also, there are few people who understand or really try to. This alienates me more from my friends now.

I have been very grateful for the support from Sibs during lockdown. The support calls have helped me to talk to someone outside the family who really understands what it's like to be a sibling carer, especially now. The online resources and the new book for adult siblings has also been incredibly helpful and makes me feel understood and that I have worth as a sibling carer and as an individual.

*All names have been changed.*

## Sally - I am an NHS worker. I can't provide care for my disabled brother because of the risk of passing on coronavirus

I am a sibling of a man with learning disabilities. I'm also a single mum and an NHS worker.

My brother moved in with my dad as an emergency placement in December due to abuse from his carers in his supported housing. It got to a point where my brother was so scared of the risk, he had to leave the house immediately. Since then he has been moving between family houses - my mum's, my dad's and mine.

In February, we requested that some care was still provided as my brother is now scared of carers and my dad is 72. My dad was spending all his days driving my brother to his different activities to keep his routine going. This was the reason he was coming to all of our houses to allow my dad respite. Since lockdown he has been stuck at my dad's.

I can't help due to my job and the risk of passing on Covid. He has lost everything, literally. The government told him to stay home, so he won't leave the house. The social worker calls him every now and then but there has been no care provided, no suggestions of anywhere he can move to. He wants to live in a flat alone with the support he requires. He didn't realise he was going to be stuck with his dad for 6 months plus. What 43 year old wants to live with their dad?

He has challenging behaviour, mostly self-neglect, and that puts a huge strain on the relationship with my dad. In terms of mental health, it's impacting on both of them. There has been one call from the community team to complete a tick box risk assessment. They called him once and told him he could go out for a walk. He still won't go out and they didn't follow up on this at all.

As a sibling I've found this really hard. I feel very guilty that due to my job I can't help him. My dad has all the strain with no carers or respite. I try my best to video call but it's not the same as being there and helping with tensions. I'm going around today for the first time to have a cup of tea in the garden (I couldn't do this before

because my son finds it really upsetting to keep a distance and now he is at school I can finally go).

I do, however, think we are lucky. If he had been in supported living we wouldn't have been able to see him at all and he would have really struggled. I see the carers in his house all masked up. It would have been scary for him.

However, the lack of social care support and this limbo we have all been in, because he can't move, has been really hard. Services always overestimate him and 6 months on we still don't have a care plan for him. We are waiting for the fight to get him the care he needs, so we have this worry hanging over us all the time.

I also really just want to give him a hug. I want to remind him that his family loves and supports him (the carers repeatedly told him we didn't). This situation really isn't helping us with improving his mental health after the abuse. I really worry about his mobility, his mental health and the fact he will have forgotten bus routes etc when he gets out again. He will be much less independent because of lockdown and that will really be upsetting for him because independence is the most important thing for him.

*All names have been changed.*

## Esther and Judith – Both our disabled brother and mum needed care during lockdown, so we divided the responsibility between us

*We are Esther and Judith. We're sisters to our brother, Jonathan, who is autistic and has a learning disability. He has a weekly routine of activities and supported training placements. In March, the café he works at closed, and the rest of his activities, including all social and sporting groups, were cancelled. This left Jonathan without any structured schedule to his day. One of his key support workers was off work for over a month, and his team was reduced to just one member of staff for the first month. Initially, dad took over organising Jonathan's care, sorting out the shopping and taking him for walks almost every day. Then mum became ill, and dad was no longer able to visit Jonathan because of shielding restrictions. Mum was in and out of hospital.*

*So we decided to divide up the care between us. Esther moved out of her flat and moved into our parents' home to take care of her Mum and Dad. Judith took on more responsibility for Jonathan.*

**Judith:** Jonathan and I have always been close, but I've never had to have a "caring" relationship with him before. I always knew that, one day, my sister and I would take on more responsibility for his care, but I never expected that to happen so soon and so suddenly. Throughout lockdown, I've been trying to give him some structure by taking him out for a long walk in the nature reserve near where he lives, 4 days a week. I've been liaising with his support staff to come up with ideas on how to talk to him about the situation, help him cope with the change in routine, and how else to give structure to his days.

It's been challenging being thrown into this role so suddenly. I'm trying to juggle it with working full time; often making up for missed work hours in the evenings and weekends. It's also been really difficult trying to manage his expectations. He knows that he can't do everything he usually does because of the coronavirus, but I don't think he fully grasps what that means. It's been hard to see him upset - sometimes to the point of tears - about not being able to spend time with the rest of our family and friends.

In the early days of lockdown, when he was struggling the most, he was often tearing up his favourite objects, biting himself to the point of leaving bruises all over his arms, refusing to engage with anything or anyone. Thankfully now the restrictions are less strict he's a lot happier and has settled into his new routine well, but for those first eight weeks of complete lockdown it was a real challenge.

**Esther:** I often feel guilty that as I can't drive I can't visit Jonathan and take him on walks like my sister does. I can't provide her and the care team with any respite. Instead I can only speak to him on the phone. This has made me feel left out. Seeing how my sister has had to cope with a full-time job, our mum being ill and being the sole family member providing care has made me feel incredibly guilty for having the luxury of not being in a place where I am responsible for Jonathan's care. At the start of lockdown I was getting video calls from him maybe ten times a day. Most of the conversations were around his anxiety at not understanding why he couldn't see family and continue as normal. It's been incredibly difficult to see him so

upset on the phone and knowing that I can't explain the situation in a way he can understand and that I can't visit him.

As I am working from home and providing additional support to my parents, the addition of ten phone calls a day really affected how well I was coping with the situation. I found myself choosing to ignore his phone calls rather than talk to him, because I didn't want to see him upset, and I didn't want him to feel jealous that I was with our parents, but he couldn't see them.

When the restrictions eased last week, I saw my brother in person for the first time in nearly 3 months. Normally I see him once a week. It was so amazing to see him again in person, and see how happy he was being out of the house and around more family members. Jonathan initially struggled with social distancing, but by the time I saw him last week he knew that we couldn't hug and had to sit far apart.

I want people to know that there are a number of different roles that adult siblings play in lockdown. In my family alone we have two distinct roles: My sister is now a carer and activities coordinator in addition to being a sister, while I remain just a sister. She has taken on so much more responsibility and handled the early challenges of helping Jonathan adjust to lockdown life.

In contrast, I've been fairly cut off from his situation and left feeling incredibly guilty that I am not helping him, I am not caring for him and beyond a few video calls I am not engaging with or entertaining him. The pressure that we, as siblings, should care for and be responsible for our disabled brothers and sisters, either now or in the future when our parents are no longer able to, is constant and has been exasperated by the lockdown. I feel conflicted, sad and frustrated by my inability to see and care for my brother. I can only imagine how much more difficult it is for people who are currently living with their siblings, providing full time care without much respite, if any.

## Devi – The last 3 months have been an endless cycle of working and caring

My brother is in his 50s and lives semi-independently with the help of myself and carers. Before coronavirus was an issue, he spent his week doing activities at a local centre and enjoyed drumming and ballroom dancing lessons. My brother has anxiety and traits of autism, so these activities were great for helping him to socialise and learn new skills and he got stability from his weekly routine.

In early march, we started to get the idea that things were going to be bad. We started to make adjustments to our lives, cancelling visits to family members and asking our elderly mother to stop going out.

As all of us have been experiencing, the Covid situation has meant all our worlds have been turned upside down. There has been a loss of routine, control and peace of mind that we had for the most part before all of this.

Supporting my family through this time has been one of the hardest things. I visit them once a week and spend the rest of the time supporting on the phone. The news was full of pictures of helpful neighbourhood groups offering to drop off bags of shopping for people shielding at home, but most people do not understand what goes into being an unpaid carer. It goes far beyond shopping, in fact shopping is the easiest thing to take care of.

The last 3 months have been spent balancing the mental and physical health of my family. I am currently taking care of 1 parent, 1 brother and 2 children of my own. All while working full-time and attempting to home-school both children.

For me the biggest challenges have been:

1. Keeping everyone safe. My mother is in the at risk group for severe issues should she get Covid, so has been told to shield. I wouldn't be able to keep my brother away from her – he wouldn't cope mentally, so I've had to try to get him to distance as much as possible when he does see her. If he was to shield with her, neither of them would cope. My biggest fear is he will bring coronavirus into mum's house and it will kill her.

2. Getting my brother to understand about distancing and hygiene. My brother is used to popping to the shops when he feels like it. I have been trying to impress the seriousness of the situation on him, but without scaring him. The panic buying at the beginning of lockdown scared him. When he went to the shops, he couldn't buy any bread for 3 days running.
3. Keeping my brother amused. When he's bored, he gets upset and he'll start upsetting my mother. His carer has been really helpful. He has been taking him for walks and playing music with him which has really helped.
4. Managing someone else's life admin remotely. I run my brother's finances and have to deal with the bank as well as local councils and the Department for Work and Pensions (DWP). This can mean long periods trying to deal with things on the phone and security measures. Despite having a registered Power of Attorney, I still have to get my brother to speak to someone on the phone to allow me to talk on his behalf which means I have to go and see him during working hours.
5. Providing emotional support. This has been the hardest things to deal with. I get around 5 phone calls a day from my brother and mother at the moment. He hasn't been well, so over the last few days it's been more like 10.
6. Other people triggering him. People don't understand the impact of seemingly small changes will have on him. He had a fence replaced at his house, but a bush was removed without telling him it was going to happen which triggered a huge meltdown. This had to be managed over the phone by me, and in person by his carer. His emotions are very close to the surface and for the most part he's been coping really well, so things like this can have a massive impact.
7. The lack of support. All services stopped with lockdown.

Without doubt the hardest thing has been that there is no time off. The last 3 months have been an endless cycle of working and caring. It is hard to sleep and I feel emotionally drained.

We have had some fun times, but the hardest thing about being an adult sibling is that I don't get to enjoy the fun side of my brother that other people see. I am the one dealing with the issues and imposing boundaries to keep him settled and safe. People don't understand the challenges and it can feel very lonely. It has been incredibly tough on my mental health. I am pulled between my brother, my mother and my family.

## Other related pages

Self-care and the coronavirus

Allie Stewart, Sibs' Trustee and trained psychotherapist shares her expertise with fellow adult siblings

[www.sibs.org.uk/support-for-adult-siblings/self-care-and-the-coronavirus/](http://www.sibs.org.uk/support-for-adult-siblings/self-care-and-the-coronavirus/)

Coronavirus (Covid-19): Useful information for adult siblings

Our regularly updated guide for adult siblings on keeping in touch, isolating together, hospital admissions, changes to care packages and more

[www.sibs.org.uk/support-for-adult-siblings/coronavirus/](http://www.sibs.org.uk/support-for-adult-siblings/coronavirus/)

*"I appreciated the document on self-care during coronavirus. It really meant a lot at the beginning of lockdown to know that you were taking the time to consider our needs, as it was a really difficult watching my parents and siblings go through such a huge change in routine and not be able to help." – Adult sibling*

## About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

Being a sibling can be a complex and challenging experience. You are not alone. Visit our website, follow us on social media, and sign up to our mailing.

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