

'WHAT WILL HAPPEN TO SINEAD WHEN WE GO?'

Our Carers in Crisis series continues. Mary and Denis McDonnell, who are both 79, cannot get residential care for their disabled daughter



Rosita Boland

For the past 53 years Mary and Denis McDonnell, who are 79, have been caring for their daughter Sinéad at their home in Douglas, in Co Cork. "Sinéad was born with cerebral palsy of a very high degree," Mary says. "She also has curvature of the spine, a dislocated hip, is doubly incontinent and is fed via a feeding Peg [tube]. She's on a lot of medication. She can't sit or turn or do anything for herself physically. Sinéad is completely dependent."

As we talk Mary has to take frequent breaks to catch her breath. She has asthma and finds it difficult to breathe. Recently she had pneumonia. Her husband is not in good health, she says. As they approach their 80th birthdays, and anticipate Mary's becoming too frail to care for their daughter, they worry constantly about her future.

"I am in the horrors about what will happen to Sinéad when we go," Mary says. "She can do nothing for herself. We love our daughter and are happy for her to be with us at home, but as carers we are a community that has been taken for granted by the Government for far too long. We save the Government so much money, and we are not appreciated for the work we do."

"As parents of children with disabilities we can't just walk away, and they know that. But it's not only our children who grow older: we are growing older too. There has never been enough money, but in recent years the situation has become absolutely appalling."

Home care

Last weekend *The Irish Times* published an interview with Johanne and Alan Powell, a couple in their 60s who are facing retirement and still caring for their profoundly disabled daughter, Siobhan. Since then *The Irish Times* has been contacted by several other parents of disabled children. Mary McDonnell is one of these.

The McDonnells do now get support, in the form of HSE-funded home care for their daughter. People come in during the day and night in shifts, to help with the Peg feed – Peg stands for percutaneous endoscopic gastrostomy – move Sinéad in the bed, change her and deal with all the other elements required for her care. It is only in the past year or so that they have received overnight help. They are grateful for this, even though it means having someone else in their home six nights a week.

Until last December the McDonnells received five fortnights of residential respite for Sinéad each year. "It's a very difficult and hard job that we do, and we need that respite, especially as we get older," Mary says.

"Last December we were told that the respite was being withdrawn by Hiqa, because



■ "We are taken for granted": Mary McDonnell and her daughter, Sinéad.
PHOTOGRAPH: DARAGH MC SWEENEY/PROVISION

there wasn't the right ratio between nurses and the people being cared for. We were told it was a 'temporary cessation of respite', but nothing has happened since. It was not replaced."

So this year, instead of 10 weeks' residential respite for Sinéad, and a concurrent break for her parents, they got one full week and two part weeks. "Two of the weeks were short weeks," Mary says. "They went from Monday afternoon, after 3pm, to Saturday after lunch, so they were just five

days, not a full week."

From Monday to Thursday Sinéad goes to an Enable Ireland care centre at Little Island, in Cork. She doesn't attend on Friday, as she's too tired by then. The rest of the time she's at home. "I don't ever want to part with Sinéad, and I love looking after her," Mary says. "I am her primary carer, but I get a lot of asthmatic attacks and coughs, and I am getting a bit long in the tooth to be doing this. It is very hard going."

"I want a home from home for her"

In the past year the couple have been looking for a residential placement for Sinéad. "I want to know that there is going to be a residential place for her, a home from

home, and I want to know that, in the meantime, there will be respite for me," Mary says. "We have been told there are no places available for her, although the HSE are well aware of our case."

Mary is weary of being taken for granted by the State and by society. "People tell us, 'You're great,' 'You're fantastic,' but we don't want them to say that. We want people to have some idea of the difficulty of our situation. The reality is that we have to shout and fight for every service."

"Funding has always been a problem, but the Government does not seem [to be] prepared to look after us, and our needs, and those of our daughter. I want the Government to finally sit up and take notice of us."



The Powells The story that 'started a conversation'



■ Family care: Alan Powell gets his daughter, Siobhan, ready to go out.
PHOTOGRAPH: BRENDA FITZSIMONS

Last Saturday *The Irish Times* published an interview with Johanne and Alan Powell, a couple in their 60s who are caring for their profoundly disabled daughter, Siobhan, at home in Co Wexford. They have been seeking a residential care place for her for three years. Siobhan is one of 61 people on a waiting list in the county.

Johanne talked about the challenges of looking after Siobhan, who cannot walk, is nonverbal, does not eat solid food and has only one kidney. The couple gave the interview because they wanted to start a conversation about the burden that falls on family carers in Ireland – work that is estimated to save the State €4 billion a year.

"I want residential care for my daughter. There is no such thing as retiring for carers unless you die... Can I survive 10 more years of this?" she asked.

"We'll need someone to wheel us around then," Alan said. "I want my life back, and my wife back."

The interviews on this page are among many responses received by *The Irish Times* this week.

You can read the Powells' interview in full on irishtimes.com

Podcast
Rosita Boland on the inside story of Carers in Crisis, at irishtimes.com

→ Catherine Cox
Opinion & Analysis

'The benefits of residential care have been immeasurable'

Tommy Davenport, who has Down syndrome, has had full-time residential care since last year. Life has improved for Tommy and the whole family

Aisling and Kevin Davenport are the parents of three children, two sons and a daughter. Their eldest child, Tommy, is now 13. He was born with Down syndrome and, at four, was diagnosed with autism.

"We had been living in Meath," Aisling says, "and we decided to move to Dublin, so that services for Tommy would be co-ordinated."

"When we moved, our social worker at the time said that residential care would be needed for Tommy once he hit puberty, so from early on that was what we were looking for."

Tommy also has insomnia, which means that for roughly every second night he will not fall asleep until midnight and then be awake at 3am.

"As he got older he became more of a danger to himself, and because he had no sense of danger he couldn't be left alone. One of us had to get up to be with him."

Crisis after crisis

When they moved to Dublin Tommy became a client of the St Michael's House services.

"When we started with St Michael's House we hit crisis after crisis. He self-injured a lot. He'd pinch his face with his nails so hard he'd draw blood. He still has marks from doing that. Or he'd bang his head against hard surfaces. He has permanent scarring on his forehead from that."

Kevin Davenport's work regularly took him out of the country, so Aisling frequently was the sole carer for their young family.

"We all became further and further exhausted and stressed. Even making dinner was a chore. There was an impact on the younger children."

my once they moved to Dublin, but it was never clear when respite would become available.

"Services are so patchy and inconsistent that it makes it so hard to plan anything."

Aisling recalls the efforts involved to attend a family wedding.

"It took four of my friends, doing shifts between them, to cover the day. Even organising the logistics of that alone meant that by the time I actually left the house I was already exhausted."

Revelation

As Tommy got older, as the social workers had predicted, his behaviour became more difficult to manage.

"He was bigger and stronger, and pushing us out of the way. He was less easy to look after in a physical way. He has a lot of sensory reactions, and when he's exhausted from lack of sleep he might hit out."

In July last year the Davenports received a residential place for Tommy at St Catherine's Association in Co Wicklow.

"The benefits for all of us have been immeasurable. With all the additional care Tommy is getting there has been a huge improvement in him. It has been a revelation."

"His care is very inclusive of us; we have him home overnight twice a month, and we see him a minimum of twice a week. We can go and see him whenever we like."

As for family life now, she says, "It took a long time to get our sleep patterns back, but now we have so many more opportunities to do things as a family – to be spontaneous – and my husband and I are a lot less anxious."

Aisling Davenport does not like to dwell on what their family life would be like now had Tommy not received his residential placement.

"We know how lucky we are," she says, "and we know how many other families are looking for placements. The conversation needs to be had about how carers in Ireland can be supported better."

ROSITA BOLAND



'I will fight for my sister when Mum and Dad can no longer do it'

Jillian Godsil

When parents of disabled children grow too old to cope, siblings often step in

Jen Corrigan is 37. She lives in full-time residential care in an attended house attached to Cheeverstown House, in Templeogue Dublin, and requires an aide at all times. She has severe cerebral palsy and has to use a wheelchair.

Jen is mostly nonverbal, although her family can understand her if she speaks slowly enough. She needs help to use the toilet, get a drink, have food, to get out of bed – everything.

She has two siblings, Niamh and Edward. Niamh, who turns 40 this month, lives with her parents, and Jen comes home every second weekend. Niamh knows only life with Jen. Everything the family has done has revolved

around Jen. It is a silent weight that never shifts. As Niamh celebrates her 40th birthday she knows that Jen may well be part of her life for the next 40 years. It is hard to explain this weight to anyone outside the family.

Niamh has seen her parents' struggle through Jen's life. Until Jen was 17 they received virtually no help. "Mum and Dad had to fight tooth and nail for every single thing. I don't understand why the system washes their hands of us. If Jen had cancer we would not have to beg for everything. It would be given to us without this constant battle. It is as if we are pariahs or something."

Schooling supports

Once Jen became an adult the schooling supports were gone, and the Corrigans feared that they would be left to their own devices.

"Mum and Dad gave the health board an ultimatum," Niamh says. "They needed a full-time package for Jen. They knew that if they did not get it the responsibility would always be ours and, in time, fall to my brother and me."

■ Niamh Corrigan, with a photograph of her sister: "Sometimes I worry if Jen will be penalised for my fighting."
PHOTOGRAPH: NICK BRADSHAW

"Even with the full-time residential care it is still our responsibility. When Jen is home everything has to be done to suit her. Dad makes her smoothies; Edward and I plan events. But mostly she wants to be with Mum. Mum cannot move without Jen going with her."

Niamh loves her sister dearly, but she does not view her as a blessing. "It is a curse," she says. "If we didn't love her it might be easier. Or if my life was minding her, maybe that might work. But, while I love her, I also resent her, and I get angry on her account."

"I will fight like a tigress for Jen when Mum and Dad can no longer do it. Sometimes, though, I worry if Jen will be penalised for my fighting. That is what makes it so hard."

"The system says you were dealt that hand and now you may just cope with it. How is that fair?"

Facebook feedback 'We are carers, but not by choice'

Numerous commenters on the *Irish Times* Facebook page have shared their experiences of caring for disabled relatives. Here's a selection of their comments.

■ Melanie Fay: "Yes, we are carers, but not by choice. My son is profoundly deaf, autistic, with severe learning disability. This is an ongoing struggle. Unless you live with this on a daily basis you will never understand how incredibly hard and tiring and emotionally draining the life of a carer can be."

■ John McNamara: "My wife and I are in the exact same situation [as the Powell family]. My son is going to be 18 in May. The only part of the article that I don't like (and may be reading and interpreting it wrong) is an implied attitude of being resentful of her daughter. Yes, her life is different than everyone else's (and so is my wife and mine), but we love our son without hesitation and realize that our life might be different, but still okay. I carry a picture in my pocket of a little girl that is going through cancer treatments. It helps my refocus on how good my life is compared to others'. The only bit of advice I can give others in my position, and this woman's position, is: you must work on yourself and make yourself the best you can be before you help and tend to others. I pray that this family finds peace and comfort in this trying time in their lives."

■ Ann Kinsella: "My parents are in their 80s and still caring for my sister, who has a learning disability. She has been under [a charity] since she was three years old. Still waiting on a residential place for her. Makes my blood boil that my mother, who has dementia, still has to be a full-time carer. I could go on..."

■ Lucy Devin: "Having watched my grandparents care for a mentally handicapped child, I have seen the toll it takes. They were lucky, in that he has a place in a wonderful facility, but then felt constantly weighed down with guilt that he wasn't at home. We need to demand better facilities and more places for families dealing with these issues."

■ Rudy A. Murphy: "I've a son with autistic-spectrum disorder and a learning disability. I've also a daughter with a heart condition. I find that children and adults with special needs are treated like second-class citizens. Reaching breaking point is nothing to be ashamed about; a lot of parents don't like to admit it."