

# ORDINARY HEROES

Family carers look after their loved ones in their home, often with little to no help from the State. Here, *RSVP* chats to carers across the country to find out about the challenges they face

A family carer is usually a relative who provides assistance and sometimes medical-grade care to a loved one who has a health condition or disability, all within the home. They often live with the person they are looking after.

Family Carers Ireland, an advocacy group who support carers, estimate that there are over half a million family carers in Ireland, and they save the State €20 billion per year by providing 19 million hours of unpaid caring work per week.

Family carers in Ireland are entitled to carer's allowance, a means-tested weekly social welfare payment of €236, but carers say it is hard to make ends meet with this payment, especially with the cost of living crisis.

## TEENA GATES

Teena Gates lives in Blanchardstown, Dublin, with her father, Terry, who is 97. Terry has dementia and Teena's caring journey started about eight years ago.

"I was working full-time in radio. I was a mountaineer, I climbed to Everest base camp, I did the Liffey and

Lee swims, I was an avid canoeist, I was very active," she recalls.

Before Terry got ill, he was very independent. He was still driving up until he had a bad fall. After this, he was diagnosed with vascular dementia, and Teena became his full-time carer.

The first couple of years of caring were very hard on Teena physically and mentally. She wasn't able to sleep properly at night as Terry was at risk of falling out of his bed. He was also prone to wandering away and had balance issues, so Teena was always on high alert to make sure he didn't accidentally hurt himself.

"It was very isolating. I couldn't really leave the house or sleep. I was fighting to get a care package, where paid carers from the HSE or an agency would look after Dad so I could get a rest," she says.

Teena's caring role took a major toll on her health. "I put on 13 stone as I was essentially housebound. I also have diabetes now. The pandemic didn't help," she admits.

During this tough time, Teena adopted a German Shepherd dog from the Dublin Society for Prevention of Cruelty to Animals, who she called Google Dog because she is great at searching and finding things. Teena adds: "When Dad first saw her he said,

“I was scared. I was close to giving up hope”



'You brought me back a horse'. She is amazing with him. She understands his needs, she calms him down, she never barks or growls."

Google Dog also supported Teena when she felt demoralised and isolated.

Eventually, Teena and Terry were granted a HSE Intensive Home Care Package for people with dementia, a relatively new initiative. "This changed our entire story," says Teena.

Terry receives 57 hours of care per week from healthcare assistants and carers from Home Instead, on behalf of the HSE. "It makes such a difference to both our lives," says Teena. "I can sleep, I can rest, I can go to the gym, I can walk the dog. I can get my own health back on track now. The manual labour of looking after a loved one is now shared."

Teena and Terry also received a grant from the local council to build an accessible bathroom and bedroom downstairs. This has also greatly improved Terry's quality of life. "He has a great routine now. He's really happy and he knows his carers," says Teena.

"He is laughing and a bit of his personality has come back. I know dementia can't be cured, but he has actually improved because his care is being managed in a way that suits his condition."

While the daughter and father are in a much better place now, Teena admits she had to fight for everything, and knows other carers are still fighting. "There should be an easier way, there needs to be some sort of centralised system or website where everything is available," she says.

"For anyone starting out on this journey, find your public health nurse, as they will let you know what you are entitled to.

"Carers are exhausted, they don't have time to go looking for support – and no-one is trying to fleece the State. We care out of love. As hard as it was, I know I did the right thing because Dad is happy."

Teena is very grateful to the healthcare assistants who look after Terry. "I was scared, I couldn't see where it was going. I was close to giving up hope. A little support goes a long way."

## BARBARA KOVACH

**Barbara Kovach, from Cashel, Co. Tipperary, first began her caring journey when she was just 12 years old caring for her grandmother. She later cared for both her parents before they passed away and today, she looks after her son Liam, 21, at home full-time.**



"My sisters also spent time living with Gran. Back then there was absolutely no support, the family did it all," she says.

In 1986, her father was diagnosed with cancer. Barbara and her family cared for him at home until his death a short time later. Her mother passed away in 2011, and all of Barbara's siblings helped care for her until her time came.

Barbara now cares for her son Liam. He is 21 years old and has Down's syndrome and autism. Liam was also born prematurely, so he has complex medical needs.

Barbara gets up early each morning to prepare everything for Liam. She makes sure he is washed and dressed and also makes his lunch. Since Liam also has an eating disorder and is at risk of choking, his food requirements are very particular. "He goes to a day centre Monday to Friday. His transport was cut back in 2019, so we drive him there, it's quite a distance away," Barbara says.

Liam – who loves music and watching TV – needs one on one attention at all times to make sure he stays safe, as he may run out onto the road or accidentally hurt himself. Barbara continues: "Our whole lives revolve around Liam.

"He is the happiest guy. It's a privilege being his mam. Not everyone has the opportunity to care for someone like Liam. He's such a loved person, I'd be lost without him."

However, when Liam gets low it can be difficult on the whole family. Barbara explains: "As his carer, it can be



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tough. When he's in hospital or he's not well, it is very hard for him. He is essentially non-verbal, so he can't tell us what's wrong."

A huge chunk of Barbara's time is spent fighting for services. "Since Liam transitioned into adult services, we have been trying to get speech and language therapy. It's just been impossible, there's been endless back and forth."

According to Barbara, people like her and her husband George give up their whole lives to make sure their loved one is well cared for at home. She continues: "We shouldn't face a constant battle trying to get services. There are not enough respite services. Unless you can afford to bring in outside help, you often get no break."

The rate of carer's allowance needs to be increased in line with the cost of living crisis, Barbara adds. "Our food and energy bills are increasing but our income is the same," she says. "When you think about it, the Pandemic Unemployment Payment (PUP) was €350. Carer's allowance isn't close to this and it's means tested."

The emotional toll of caring shouldn't be underestimated either. "You can get depressed, frustrated and very isolated," she tells *RSVP*.

At the moment, the family's housing situation is precarious as their landlord has given them notice to quit. The family have been accommodated in a rented house under their council's Rental Accommodation Scheme for over a decade. Barbara says: "The owners need to move back into their house as it's their retirement home, which I totally understand.





"We are out of our minds with worry at the moment about what sort of accommodation the council can provide. Liam wouldn't do well in emergency accommodation."

Barbara says people don't ask to become a carer, it is just something that happens. "You'll either need a carer or you'll become one."

## HARRY FLYNN AND MARIA CONDON

Harry Flynn from Ferrybank on the Waterford/Kilkenny border is a young carer. He is currently studying for his Leaving Cert. He and his sister Molly help look after their youngest sister Isabelle. Back in 2018, they won the Young Person of the Year award. Their mum Maria Condon is appealing to the Government to start caring for carers.

Isabelle was born with a condition called sleep apnoea

which means she could stop breathing randomly throughout the day and night. She also has cerebral palsy. Both Harry and Molly have performed CPR on Isabelle numerous times, saving her life.

"I've been doing that for the past six years," Harry says. "I have to bring her back. Sometimes Isabelle has problems with her mobility, so every morning we do some exercises to help her muscles move so she can get out of bed, and we go swimming every Friday."

Getting access to services for Isabelle has been a struggle however – especially physiotherapy. And while he's not sure yet what he wants to do after he leaves school – he is currently considering doing a Bachelor of Arts degree in Waterford – Harry is confident he will eventually work in an area where he can help people.

But young carers, he says, need more support, especially when it comes to education. He has missed a significant amount of school and young carers like

him are not given any exemptions or extra time to catch up with their studies.

Maria, Harry's mother, says their stories need to be told. While Harry's school is very supportive, they can't do anything about the way the Leaving Cert is designed or marked. "His circumstances are not taken into consideration," she tells *RSVP*.

Maria adds that people are not aware of the difficulties family carers face and the impact these issues have on family life. "While caring is so rewarding, you have to fight for everything," she reveals. "We've been passed between services, it seems like no-one gets together or talks to each other." According to Maria, until the Government starts to care about carers, nothing will change.

In a statement to *RSVP*, the HSE said it recognises the contribution of carers who care for family members, relatives and friends. "The HSE acknowledges that deficits in service provision and waiting times for some services at this time are not appropriate and particularly stressful for service users and their families or carers.

"The HSE is also very much aware of the importance of timely and appropriate service provision for the families of both children and adults and the impact the absence of these services can have on family life and on the ability of people with disabilities to fully participate in their communities."

The HSE said 1,000 General Employment Permits for non-EU/EEA citizens were made available for home support workers from January 2023, which should reduce waiting

lists for the Home Support Service. The HSE added that therapy services in the community prioritise patients identified as having the greatest needs and the highest risk.

"Community-based care is currently undergoing substantial reform in line with Sláintecare. This involves a significant restructuring in how services are delivered to ensure that care is provided in an equitable, efficient and integrated way through newly established Community Healthcare Networks."

■ For more information visit [familycarers.ie](http://familycarers.ie).

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Words by **Aine Kenny**

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