

# 'This is my brother, he has a tube'



**Sheila Wayman**

Childhood is different for siblings of a child with a life-limiting condition. A young mother from Dublin tells her story

It is hard for Niamh O'Shaugnessy to spare her three-year-old daughter, Indie, from the raw reality of having a little brother with a life-limiting condition.

Two-year-old Ollie, who was diagnosed with spastic quadriplegia cerebral palsy last May, regularly has epileptic seizures. As the only adult in their Belmayne home in Dublin 13, Niamh has to reassure Indie when Ollie is having a seizure, while simultaneously attending to him.

"You have an upset three-year-old not knowing why her brother is lying there shaking," says the 27-year-old mother, whose relationship with her children's father broke down soon after the birth of Ollie. "Unfortunately, I can't take my daughter out of that situation. Sometimes, she has to see things I don't want her to see. But then why hide her family, because this is her brother? No matter what age she is, this will continue to happen."

Childhood is inevitably different for siblings of a child with a life-limiting condition. "The positives for them are they have a huge amount of empathy and compassion," says Sinead Moran, nursing manager with the Jack and Jill Children's Foundation.

"They see the world very differently. The negative is they want the normality of life and they don't have it. They have to adjust to a new norm, which is very difficult."

There can be jealousy when the child with special needs always takes priority. Siblings have to live with the fact that birthday celebrations, outings and holi-

day plans can be swiftly cancelled if that child gets sick.

During 20 years working with Jack and Jill, which funds home nursing care for more than 400 families, she has seen that siblings need to be kept informed, in an age-appropriate way, about the child with the disabilities.

"Siblings want to help, they want to care, they want to be told what is wrong with them," says Moran, who did a thesis on the impact of having a brother or sister with a life-limiting condition for a master's degree five years ago. If they're kept in the dark, they will be constantly worrying.

Parents feel guilty because they can't give time to both. "I suppose that is where I have seen the difference our hours make," she adds.

"It allows them to give that time."

Niamh, as a single mother, uses many of the hours of nursing care for Ollie to spend one-on-one time with her daughter. Having had a difficult childhood herself, she is intent on teaching Indie "to be grounded in herself".

"I grew up around trauma as a young child," says Niamh, who went into residential care. "I see these things with Indie, having a special needs brother, that this could trigger a little trauma for her, when she is aged six-eight. She is a really intelligent little girl, in advance of herself. She picks up on everything, emotions, actions. She is very in tune, which is brilliant, but sometimes I think she takes on too much by being in tune."

Indie adores Ollie, whose "smile lights up a room". She likes to introduce him to people, explaining "this is my brother, he has a tube", referring to his nasogastric feeding tube.

## Conversations

But Niamh does not want her to feel burdened with responsibility. "I like to have conversations about her mind, her body and her soul. I know a lot of people look at me in a weird way when I say that about a three-year-old."

"I feel if I didn't have Jack and Jill, I would not be able to put so much time and effort into that with Indie. It is huge to me."

She says she likes to do activities with her daughter that are free and involve nature, "so she can continue this way of life when she gets older. I don't want her to feel when she's overwhelmed that she



needs to go and get her nails done".

"Me and Indie like to go and get our nails done as a treat," explains Niamh, a beauty specialist, "but I always let her know it is a treat and would not be a regular thing."

She wants Indie to grow up knowing that the best way to deal with mental pressures is to go for a walk or a jog.

Niamh also uses some of the 60 hours a month respite to take time for herself. It means she can have at least one day a week when she doesn't have to be a carer.

"I am very grateful to be able to do this for my son, but at the same time, us mothers need a break - burnout and exhaustion is a real thing."

Early on in Ollie's life, Niamh really

struggled and wasn't eating. "I was down to 52kg [8st 2lb] and my shoulders and back were physically sore. I remember sitting down and crying and saying this can't be my life, just being at home, like a robot."

Broken sleep is a constant challenge. "Ollie is awake at 5am every day, and will also wake up during the night and be quite stimulated." The noise may wake her daughter too.

Indie attends a creche, which is a great social outlet for her, says Niamh, who has just one sister in her life and she doesn't live nearby.

Undoubtedly, there are times when her daughter feels jealous of all the attention her mother has to give Ollie.

"I think Indie can get quite annoyed with my attitude. She is a three-year-old and she will cry for silly things and I am the type that says, 'Do you know how lucky you are that you can do that? Because if your brother could do that...' And she will kind of go 'humpf' - as if to say, 'I didn't ask you for that opinion.'" Niamh laughs. "It's about giving Indie that selfish time in a healthy way. It is really, really hard to balance that."

But she is philosophical about the challenges life has thrown at her, both as a child in care and now as a parent. "I haven't got the support of a mam and dad through life."

But, "I have learned that life is beautiful and it's what you make of it. Just because

**Niamh O'Shaugnessy, with her daughter Indie (3) and son Ollie (2), is philosophical about the challenges life has thrown at her.**

PHOTOGRAPH: ALAN BETSON

people have let you down, you don't need to let people down. You stay true to who you are - that is how good comes."

Registration for the Inognito 2023 art sale, in aid of the Jack and Jill Children's Foundation, opens on March 31st. Each postcard-sized original artwork costs €65 but the identity of its artist is only revealed after the sale of the 3,000-plus individual pieces take place on April 26th. See [incognito.ie](http://incognito.ie)

## 'I remember lying in the hospital wondering would I ever be able to take care of this child at home?'

### SHEILA WAYMAN

Concern about the baby's small size at the end of Dawn Dunbar's pregnancy was the first hint that there might be a problem with her second child. But, after her labour was induced a little early, Cathal weighed in at 2.5kg (5.5lb) and didn't need special care. However, the paediatrician recommended testing him for cytomegalovirus (CMV), which is harmless to most adults and children but can be dangerous in the womb.

"Usually hearing is the problem but that was fine; all his blood tests were fine but when they did a urine test, they did find he had CMV," she says. "Not many people have heard of it, but it causes a huge amount of disability in children. We were on the unfortunate side of the scale, it was so severe."

The levels of infection weren't particularly high, but it had hit Cathal just at the time his brain was developing, resulting in spastic quadriplegic cerebral palsy. He has a severe form of epilepsy, is non-verbal and has difficulty swallowing.

The diagnosis came after an MRI scan at

six weeks confirmed damage to the brain and Cathal was admitted to Crumlin children's hospital to have anti-viral medicine administered. Suddenly, the happy visions Dawn and her husband Jamie had of what it would be like raising Cathal alongside his big brother Conor, who was 23 months at the time, were shattered. "I remember lying in the hospital wondering would I ever be able to take care of this child at home? He wasn't in great form in the hospital, on medicine that wasn't very nice. We felt sorry for ourselves, we were grieving."

Other children were coming into the hospital to get better and she and Jamie did not know what the future held for their family. Cathal was about six months old when a disability nurse referred them to the Jack and Jill Children's Foundation for nursing care support at their home in Ferns, Co Wexford. They have been able to use those funded hours ever since in whatever way suits their family. Early on, Dawn used to take the care in twice weekly blocks of five hours; one she would use for catching up on chores but the other she would spend with a friend who had a child



**Dawn Dunbar and her family with their sons Conor and Cathal; the family will not be eligible for Jack and Jill support much longer because Cathal will turn six on March 14th**

of a similar age to Conor and they could play together.

"That was my saving grace. I had a couple of hours to get away and pretend that everything was okay even though our world had fallen apart and we were grieving very hard."

For Conor, who will be eight in April, there was a dawning realisation that Cathal is a bit different. His parents have been very open, explaining that Cathal got sick while he was in her tummy, that his brain is affected and there are things that other children can do that he can't do to the same extent. She remembers when Conor was nearly three, he noticed that a family friend's baby was starting to reach out, even though she was younger than Cathal. "Conor said to me, 'Mummy, why does she grab and Cathal doesn't?'" For a long time afterwards she could see Conor trying to get Cathal to grab by presenting

him with a toy and explaining to him it was very easy to hold, he just had to put his fingers around it.

"They have a lovely bond," says Dawn who sometimes has to rely on Conor to keep his brother entertained while she is getting jobs done. "He does have a bit of responsibility and I don't see that as a bad thing." At the same time, he is able to tell her when he's tired of doing it.

Although Cathal needs a lot of his parents' attention, she has never seen Conor get jealous over that. "He's never said anything but I think that is due to the fact that we have Jack and Jill care and we can focus on Conor for periods of time. Conor has never had to miss a swimming lesson."

Currently on 20 hours a month, they schedule some fixed time, but the carer will also respond very flexibly to help them keep life as normal as possible for Conor.

For instance, if he is having friends around for a playdate, Dawn likes to be fully available when there are other children in the house.

Unfortunately, the family will not be eligible for Jack and Jill support much longer because Cathal will turn six on March 14th and the charity can only cover children aged six and under. The Dunbars have applied for HSE nursing assistance instead but do not expect the same continuity of care or flexibility.

"I won't be able to leave the house," she says in reference to the "in loco parentis" rule that the HSE introduced some years ago for paediatric homecare nursing hours, requiring parents to nominate another person to be there if they want to go out. However, Minister for Health Stephen Donnelly said in a Dáil written answer last November that the HSE had told him it was not currently implementing that rule. Instead, it had introduced a "planned parental absence guideline" that could be agreed at the start or in a review of the homecare package.

While that might allow a parent, after a risk-assessment form has been completed, to leave to pick up another child from school, there isn't the flexibility for a parent to go to the gym, says Sinead Moran, a nursing manager with Jack and Jill, or to get away for two to three hours. She believes the bureaucracy is unnecessary. "If a child is sick, none of the parents would leave. They won't go far, they'll stay around."

But a knock-on effect of these operating procedures, she reports, is that families who may already have substantial home care packages from the HSE, still need Jack and Jill to fund day hours that they can use flexibly.

Cathal started in mainstream school, Scoil Naomh Maoldhóg in Ferns, last September, which delighted his big brother. It has also enabled Dawn, a primary school teacher, to go back to work on a job share. "Conor is so proud, pushing in his wheelchair in the morning," she says. "He comes home to tell me that Cathal is really popular with all the girls. He keeps an eye on things but, at the same time, he gets on with his life as well."

He does express sadness if Cathal is going through a tough time with seizures. On the flip side of that, when he came home from a recent sleepover with his cousins, he observed that they fight quite a lot, adding "I am kind of lucky to have Cathal, he never fights with me". His parents try to focus on the positives with him but naturally, between themselves, have concerns about what might lie ahead.

"Cathal is Conor's only sibling and we do wonder, number one, if we will be lucky enough to have him into adulthood and, number two, there is the worry if we go before him, where does that leave Conor? Obviously, you can't think too far ahead or you would drive yourself mad but it is something we do discuss."

"The thoughts of Cathal going into full-time care would be horrendous; equally the thoughts of Conor being burdened with a disabled brother," she says and, although unsure about expressing it like that, "it is a burden to carry in many ways", she adds candidly.

"Obviously Cathal has brought us lots of joys and lots of love but it is intense caring for somebody with a disability. We are able to do it because we have support but we don't know what the future holds for the boys and that is something we worry about."

## Alzheimer's sweeps an eraser across the blackboard... we are all dust

### Anthea Rowan Dementia Diary

The drip-drip of memory loss becomes a river, then a deluge and now a waterfall. Within hours, they are gone

Do you ever wonder how a memory forms? Does it crystallise, images tightly bound by place or time, a seed, an acorn to a mighty oak tree, the branches of interconnectivity? "Remember this, remember that, remember when, remember them?"

I never use the word remember in conversation with Mum.

How does a memory take root safely so that it sustains, deep and permanent within the structures of the brain? An archive of our past neatly filed away for reference later. A map: the who and why and where of every part of us.

Do you ever wonder how long it lasts: that memory, once planted? I used to: I used to guess at how far back my mother

could remember. Twenty years? Thirty? Dementia sweeps an eraser across the blackboard where her story was written; it laid waste to the most recent first: her grandchildren, first, then her children, my father. We are all dust.

But every day now, the memories I used to imagine she might still be able to form, die faster. There's nothing to nurture them. They are shallow and weak and easily pulled.

How do I know?  
Mum has a dentist appointment. A wobbly tooth has presented.

"It's sore," she complains. There are only so many days I can responsibly feed her ibuprofen before I understand the inevitable cannot be put off and the tooth must be pulled out.

I hate dragging Mum away from the sanctuary that home is, the place and people a tidy little organigram that lends context and construct to a coming-undone world. She might not know where we are (England, somewhere-in-Africa, Ireland). But she knows she's at home.

The morning dawns and Mum begins to articulate anxiety about our outing.

"Am I making too much of a fuss?"  
She doesn't wait for an answer: "I think I'm making too much of a fuss."  
I know what she is doing: she is willing



**The morning dawns and Mum begins to articulate anxiety about our outing to the dentist**

me to cancel, to call it all off. Leaving the safety of her bubble is frightening. Where is she going? She has lost all her bearings, the name of a town would mean nothing. Who will we meet and has she met them before? She does not want to appear a fool when she doesn't recognise them. And her incontinence distresses her.

She can't understand why it happens so is never comforted by my explanations ("You're old Ma, and you've had three kids." "Three?! Isn't it more than that?" "No Ma, just three.")  
Nor does she remember she wears adult

diapers that will protect her from the embarrassment of leaks.

"We need to get this seen to, Mum," I urge gently, "your tooth, whilst we can, whilst the dentist can see you", before it flares into an infection I cannot manage with my over-the-counter approach.

"Yes, yes, you're right," she agrees reluctantly.

Then, out of nowhere, "He's not going to take a baby out is he?"

"A baby?"  
And I am reminded of a rule I've recently made for myself: make no assumptions about dementia - if I thought her anxiety was about leaving home, it might as easily have been because she has forgotten what dentists do.

"No, Ma," and I can't resist a smile, "not a baby, just a tooth, the dentist might have to take the tooth out."

Which is exactly what he does. I primed him in my text message. She has Alzheimer's. He faces Mum and sweetly describes what he is going to do and why; he speaks to her as he might a child, he stoops to face her. Mum listens intently, her eyes round. He explains that he will inject her gum to numb the pain. I stand behind her, prone and vulnerable in the dentist's chair, and I murmur reassurances, keeping my hand on her shoulder.

She is baffled by the deadening sensation of gums: "I can't feel my face," she says, looking worried. I pat her gently: "It's okay Mum, it's okay."

She moans as the root is pulled. I am briefly alarmed, what if she does not understand we are trying to help and reacts to what must be painful and frightening, what if she lurches forward. But she doesn't; she just moans softly like something trapped and tired.

**Dazed**  
And then it's out and her mouth pours blood. Mum looks about her, a little dazed.

"All done," we say, as if she were seven. And Mum gives us a little smile.

You don't think about taking dementia patients to the dentist. You forget that in the falling apart of their cognition, their ailing, ageing physical selves have the propensity to fall apart too: joints, eyes, teeth, bladder, bowel.

And you forget that in facing the enormous prognosis of dementia, there are still the small everyday ailments that need addressing: a fungal infection between her toes, a sore throat, wax in her ears. A toothache.

But when we get home, as soon as we get out of the car, Mum begins to fret: "What is this place? Where are we? Why are we

here?" Her face is creased by consternation.

"This is home, Ma," I say, "we left early this morning, for the dentist."

(Remember?)  
She won't have it. She grows agitated, she casts about herself as if she's misplaced something.

"And where are they?"  
Where is who?

"Them, them," she is almost hysterical: "The people who lived here."

Me Ma, I lived - live - here.

No, she insists: "No, no, I can't believe they just upped and left without saying goodbye!"

They didn't Mum, they - we're - still here.

"What's your name?" she suddenly shouts.

"Anthea, Ma, I'm Anthea."

"No, no, you're not," cries Mum. "You're not Anthea. Anthea's gone. I can't believe she left and never said goodbye."

And that is how I know.

Dementia punctures memory so that our stories drip out. One by one, at first. A dropped name, a lost event. But time shears those holes wide; the drip-drip of memory loss becomes a river, then a deluge and now a waterfall.  
Within hours, they are gone.



# We need to talk about excess body fat – and sooner rather than later



**Sheila Wayman**

Conversations must be held 'before obesity complications set in', experts say

**R**eluctance of patients to seek advice about excess weight and hesitation among healthcare professionals to offer it leads to a huge time lag between onset and treatment of obesity.

Research in the UK among people living with obesity found it had taken them nine years, on average, between starting to struggle with their weight and having a conversation about it with a healthcare professional. There is no reason to think it is any different on this side of the Irish Sea.

"That is a long time and that is a conversation that is often prompted by some other health complication," says dietician Karen Gaynor, a committee member of the Association for the Study of Obesity on the island of Ireland (ASOI). "So people aren't having that conversation early enough in order to prevent the complications of obesity."

Primary prevention to avoid the development of excess weight involves the lifestyle measures we should take to reduce the risk of any chronic disease such as cancer, diabetes, heart disease, as well as obesity. These include healthy eating, sufficient physical activity, good sleep routine and management of stress. In the context of obesity, we should be talking more about earlier secondary and tertiary interventions, she says.

This week, from May 17th to 20th, some of the most up-to-date research and thinking about this chronic disease will be shared among 1,800 participants at the 30th European Congress on Obesity (eco2023.org) in Dublin's Convention Centre. Ireland is hosting the event at a time when the Government and the HSE have made addressing obesity a priority, says Gaynor, who is programme manager with the HSE Obesity National Clinical Programme. Yet, historically, there have been very limited specialist services here and that situation won't change overnight.

## Specialist services

A Model of Care for the Management of Overweight and Obesity was launched on March 4th, 2021. But a HSE spokeswoman says that, "to realise the benefits, in health and economic terms at individual patient, health service and societal level", a 10-year time frame is recommended for its full implementation.

Expansion of specialist services for adults and children has started, along with the setting up of new community-based multidisciplinary obesity management services in Dublin and Waterford and dietician-led, community-based obesity management programmes within the HSE's enhanced community care chronic disease hubs. Meanwhile, last October, Ireland became the first European country to adopt new clinical practice guidelines for obesity care based on Canada's pioneering approach.

"We know that 60 per cent of Ireland's population have a body mass index (BMI) of over 25; by that measure they are classed as overweight (up to 29.9) or in the obesity range (30 or over). "What we are not so clear about is the exact percentage who have excess body fat impairing their health," Gaynor says. That, not size, is what matters.

On an individual level, the only way to find out is to have that conversation with a doctor who can run relevant tests to see if



excess body fat is impairing your health, or likely to be soon. Perhaps there is a complication brewing, she suggests, that could be caught before you arrive in the GP surgery with fatty liver disease, diabetes or heart disease.

The focus of any treatment should be health gain rather than weight loss. "It's not really about the shape and size, it's about how is this impacting on your health," she says.

As weight goes on, people's bodies store fat in different places and in different ways. If it is being stored under your skin and on your legs and thighs, that does not tend to impact your health as much as if your fat is stored around your middle and around your organs. "And BMI isn't going to tell you that, it's only a measurement of size."

Stigma and misunderstandings around obesity, among both patients and health professionals, are delaying intervention, says Gaynor. To people living with obesity, she would say: "It's not your fault and it's not your responsibility alone to fix. It's a



**■ A photograph supplied by Obesity Canada 'in an effort to reduce pejorative portrayals of persons with obesity in media reporting and provide a fair and non-biased representation of youth and adults who have overweight and obesity'. Left: Karen Gaynor, programme manager with the Health Service Executive's Obesity National Clinical Programme**

biological issue." While they might believe that if they only dieted harder and exercised more, they would get the desired results, their body is primed to fight against that.

"We know diets in the short term lead to weight loss, but that weight will go back on. That just shows how complicated this disease is." Even after treatment as extreme as bariatric surgery, people are at risk of regaining the weight.

"The message we want to get across is go to your doctor, have that conversation, run those tests. You could be absolutely fine and they will say 'come back in a year' or it could be 'there is something off, let's watch that'."

Stigma is also a barrier to healthcare professionals raising the issue with patients. "They will think that maybe the individual in front of them isn't interested or isn't motivated to lose weight and there is no point in bringing it up," says Gaynor.

"Or, it is a very sensitive topic and some healthcare professionals don't feel equipped to have that conversation; maybe they feel they don't have the time; maybe they have their own struggles or issues with weight. It's a very difficult conversation to bring up and healthcare professionals do need support and training around that."

People tend not to go for treatment for excess weight until complications set in, agrees Susie Birney, executive director of the Irish Coalition of People living with Obesity (ICPO). In your 20s, the "roller-coaster of lose, regain, lose, regain" is about your looks and not being able to get clothes in your size, she says. Later, it becomes more about your health.

If both external and internalised stigma prevents people seeking treatment for obesity in the first place, it's even worse

second time around. After you have had treatment, with professionals having worked with you, your family delighted to see you healthier, there's huge shame if it happens all over again. The relapsing nature of the disease tends to be overlooked, she says.

"It is not that you have failed the diet or the treatment; the treatment may have worked, but then at some point it may fail you because your circumstances have changed."

"If you already live with obesity, you need treatment. But people who have had treatment still need prevention because it is a chronic relapsing disease. You may lose weight and get healthier through treatment, whether it is through bariatric surgery or lifestyle management, but, because obesity is complex, something can happen that will trigger you."

After surgery, somebody with obesity might drop from 25 stone (159kg) to 10 stone (63.5kg), she says. "They are living their best life; they don't need a seat belt extender on the plane, they can fit in the car and they can buy clothes in Penneys. Then when the regain comes, it's that devastation, it's back, and the shame."

While Birney has neither gained nor lost weight in the past 18 months, she says "I am looking at pre-menopause now and my treatment may need to be adjusted."

She is 16 stone (102kg) and knows people look at her and think she needs to lose weight. "I don't, because I am actually probably at the best I will ever be right now because of everything that has gone against me. I am at my best health and all my bloods are fine."

However, she fears the menopause "could skew everything for me and I will be back to the drawing board". Although her behaviour won't have changed, she knows others will "assume I'm overeating or stopped walking; it's outside factors people don't understand".

When it comes to the lack of patient-doctor conversations about excess weight, she believes the issue is not so much that GPs should raise it sooner, but how they broach the topic.

For somebody attending a GP on a bad day with some completely different health concern, a "can we talk about your weight?" is not likely to be well received, she points out. "If there was less shame around weight issues, more patients would be prompted to talk about it first."

It would be great if every GP knew how to talk about obesity and could refer their patients to services, she adds, "but our system couldn't cope with that. It's a vicious circle".

## Greater scientific understanding

Birney will be one of 14 ICPO members participating in the congress, along with another 44 patient advocates from across Europe, and they will report back daily to support groups. She believes the four-day event will be "invaluable" in raising awareness and sharing knowledge.

"You don't realise the reality of obesity until you hear the experts talking about it and you hear the lived experience talking about it. When you have the two, it gives a clear understanding."

Despite greater scientific understanding in recent decades of body weight processes, a societal belief persists that thin is desirable and equals healthy, while big or fat equals unhealthy.

"We've seen internationally that as much more effective, new-generation drugs to treat obesity become available they are being 'hijacked' by people who want to become thinner," says Gaynor, "which means the people who need it to become healthier aren't getting it. It's just disappointing."

There are genetic, environmental, health and social layers to obesity, all affecting calories in and calories out. But it doesn't stop there because, back to biology, we now know that one person's body uses calories differently to another.

There is no one single fix to obesity, "this is cross-governmental, cross-societal," she stresses.

"It needs to be everyone's business."

## Gerry's story 'The food was controlling me, rather than me controlling the food'

**Gerry Barrett (63) never had weight issues as a young man, when he liked to train five or six days a week, doing weights, karate and other physical activities.**

It was after getting married in his 20s and starting a family that he began to put on weight. With a broad, 6ft 1in (1.85m) frame, he says he was always able to carry a lot of weight and has worked continuously in telecoms since he was 17.

"By the time I was 40, I was probably 22-23 stone (140-146kg) and I finally went up to my highest of 28.5 stone (181kg)."

Over the years he attended weight-loss organisations. "I would always lose about 2.5 stone and then I would stop and put the 2.5 stone back on again."

Barrett, who lives in Ballivor, Co Meath, was reluctant to go to the GP about it. "I felt as a man I should be able to sort these things out. And I didn't want, to some extent, I felt as if I had failed."

He looks back now and sees he had developed an addiction to food. "The food

controlling the food."

But that insight came only after exploring both the medical and psychological reasons for overeating at the public weight management service in St Columcille's Hospital in Loughlinstown, Co Dublin. It took him about six years to get into that service, such is the demand.

"What really turned the corner for me was being diagnosed with diabetes type two in my early 50s. Then I got sleep apnoea and I was diagnosed with atrial fibrillation. The real killer was when I went to the doctor, I was getting blood tests every six months, and he said to me, 'Gerry you have to do something about your weight because I have to increase your diabetes medication because your bloods are still high.'"

That gave him new resolve to tackle his weight. Weight-loss nutrition products worked for him and he lost about four stone before he was due to have a gastric sleeve operation in Loughlinstown four

the need to go ahead with surgery when he was doing so well, he reckoned he was in good shape for it and, having been on the waiting list for years, didn't want to postpone. "I had the operation and it changed everything."

He started getting back into bushcraft and other nature-related activities he had been involved in with a group of friends, enjoying camping out around the country and going over to the UK for events. "We just have so much craic and I wouldn't have been able to do that if I had stayed how I was."

Between using the nutrition products and surgery, he lost about 10 stone (63.5kg) altogether. However, over the past year he has noticed his weight beginning to creep up again. "I need to knock it on the head," says Barrett, who was at the GP to discuss this the day we speak. "I need to get back on track. I want to get back down to 17 stone because I remember how well I was and how well I



**■ Gerry Barrett: I felt as a man I should be able to sort these things out... I felt as if I had failed**

# 'Have you got her a toy cat yet?' I was once appalled by this question

## Anthea Rowan Dementia Diary

Twelve months later, I realise Mum seems to feel more comfortable in the company of animals

**A**n acquaintance asked, "Have you got her a toy cat yet?" Reading my expression as one of incomprehension, she elaborated: "You know, a teddy-bear cat – something she can pet?"

A year ago my understanding of the raw end of dementia was less well developed than it is now. I was still straddling an innocent's position of denial and disbelief. So the look on my face that day wasn't just because I didn't grasp the question.

It was because I was appalled by it. A toy cat?

er's on her fourth," she said. "She strokes them until their fur falls out. When they're bald, we just buy her another one."

Just buy her another one. Twelve months later, though, with Mum much more frail, and I can see where that cat-woman might have been going with this: Mum seems to feel more comfortable, confident, in the company of animals than humans.

My fat neutered cat ("Is it a she?" Mum asks several times a day. "No ma, it's a he" – was a he) is greeted with enthusiastic calls of pusspusspuss every time he appears.

Mum rises from her chair, as the cat weaves his way plumply through the door. Seeing where she's headed, towards the tea-making paraphernalia, the cat gathers pace and trots alongside her. Mum begins to dig about for treats for him. I used to keep a bag of cat biscuits in her room so she could feed him. Every time he miaowed, she poured him another bowlful and his already ample girth grew rounder, and I feared he may keel over with furred arteries. I took the biscuits away. The cat, not surprisingly, turned his nose up at the peppercorns Mum dribbled into his bowl instead.

My Labrador has taken to sitting as close to Mum as she can during meals. When she

thinks I'm not looking, Mum tosses her all manner of treats: toast crusts, a biscuit, a bit of banana (astonishingly, for a Labrador, she declined) and many, many cheese crisps.

"Stop feeding her at the table, Mum," I reprimand. "She's going to start begging." Sorry, says Mum. And – forgetting my stern words instantly – is at it again minutes later. Dementia, in this case, is a dog's best friend.

## Laughter

Oddly, when the dog went to the vets and was incarcerated for three weeks post surgery, Mum didn't forget about her or why she wasn't with us. She asked about her every day and reported on her progress to anybody who called: "Jip is still at the vet having an operation" on her (variously) foot, leg, tummy or head.

Mum was thrilled to see her back. Almost as thrilled as Jip was to see Mum: she went barreling into her room impeded by a bucket collar to stop her chewing stitches out, which made Mum roar with laughter. And then the toast crusts and biscuits and crisps got thrown about again and I could hear Jip scabble, hampered by the collar, to retrieve them.

"Mum! Stop feeding her!"



**■ Anthea's mother greets the cat with enthusiastic calls of pusspusspuss every time he appears**

"Oh sorry, I forgot." If Mum remembered Jip, the cat didn't and was disgusted at the arrival (return) of the apparent newcomer. He sat up high glaring crossly down at the very animal that until three weeks ago he'd shared a bed, often a bowl, with. So disgruntled was he that he was forced to find somewhere

new to sleep and why not try your luck with the peppercorn dispenser again (perhaps she'd have kibbles this time?)

One night not long after Jip's return, I woke in the small hours and noticed my mother's bedroom lights ablaze.

On inspection I find her up, chatting to the cat who is threading his way perilously between her ankles.

"Mum, what are you doing? It's two in the morning!"

"Is it?" She doesn't look as if she cares. She doesn't even comment on the hour.

"Well, puss and I were very cold so I thought I'd get up and fix us both a snack – a cup of tea for me and something for puss."

## Disarray

Something for puss turns out to be a gloop of Weetabix, hot water and about 17 spoons of sugar. He sticks his nose into the bowl briefly, then stalks off. I urge Mum back to bed but she's still fretting about the cat.

"Where is he? He was freezing." (He wasn't, he has a thick coat and walrus-like blubber as insulation.)

"He's gone rattling," I lie. The cat is watching me beadily from the door hoping I might push off and let Mum get round to finding him something else to eat.

"When I check on Mum again at a civilised 7am, her room is in disarray. Momentarily, I wonder if she has been hunting down the cat again or, rather, trying to pin it down. But that's not why. She is in a state of undress because she has soiled herself in the night. Faecal incontinence is the latest symptom of all this. It's everywhere."

The cat long gone. I clean Mum up, mop the floor, strip the bed, chuck the whole lot into the washing machine. This is our reality now. Adult nappies and eternal laundry and conversations that go round and round and round.

You think, every time the disease plateaus and you find a new equilibrium, that things can't get worse. But they do. They always do: that's the nature of this horrible downhill disease.

With sad resignation I punch "dementia toy cat" into Google. There are dozens at Amazon. I am strangely heartened. Because I am reminded, again, I'm not on my own in this.



# Pádraig O'Moráin



## We fear saying the wrong thing to a bereaved person

**Y**ou lose a loved one to death and then you lose contact with people who avoid you out of embarrassment. The first time I heard of this phenomenon was a couple of decades ago; the most recent time was this week. Why does this happen?

Not only do people not know what to say to a bereaved person, they also fear saying the wrong thing. And it's easy to pop into a shop or cross the road to avoid being seen.

Yet all too often the person who is being avoided knows what's going on. After all, that person may have done the same in the

past as you are doing now. We've all done it. And we're right in the sense that trying to think of something comforting to say can, indeed, be a mistake. "At least his suffering is over" doesn't help the one who is grieving and whose suffering is very much happening right now, for instance.

But the real mistake isn't to say something ham-fisted. It's to say nothing at all. "I'm sorry for your loss" or "You are in my thoughts" acknowledges what the bereaved person is going through. That's the human acknowledgment people need.

The pandemic made matters worse and many bereaved people must be going around with an extra burden of pain for which they didn't have an outlet during the lockdowns. There's a certain comfort in funerals, wakes and the busyness that surrounds a person's death. It gets those left behind through the early days of the loss and allows them to experience the fellowship of their community. The pandemic took that away from some thousands of people, a good many of whom will still be carrying the wounds of that extra isolation and of the absence of the normal rituals.

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It's still not too late to tell people bereaved during the pandemic that you are sorry for their loss. As the Irish Hospice Foundation (IHF) says on its website, don't assume people are "over it". Don't avoid mentioning the person who

has died, the IHF also says.

When my father died I recall the GP saying to my mother to mention his name in the house every day. We did, and I think it helped. Those for whom it is a rule never to mention the dead person again are, I think, imposing a great emotional strain on themselves and on others. These may include family members who really need to talk about the loss.

If you want to offer specific, practical help to a grieving person, the IHF says, "try not to make vague offers of help like 'call me if you need anything'. Bereaved people may find it hard to reach out and ask for help. Make specific offers of help - cook dinner, cut the grass, go for a walk with them, etc".

What if the bereaved person is grieving in a situation that makes it even more difficult for others to sympathise? This is sometimes called "disenfranchised grief". It's not that long since the unmarried partner of a deceased person might not be acknowledged and might not get the normal community support. The same would go for the surviving partner of a gay person. I hope this happens only rarely

now but I wouldn't be surprised if it still happened sometimes.

Still, people can find it hard to go up to the parent, say, of someone who took their own life and sympathise with them. But that person still needs the death and grief acknowledged. It's still the case that instead of trying to think of something special to say, a simple "I'm sorry for your loss" or "I was sorry to hear about so-and-so" will do.

The IHF page referred to above is called "Someone I know is grieving". I also want to mention here a free app for people who are grieving, produced by the Australian Centre for Grief and Bereavement. It's called MyGrief and it is available for iPhone and Android.

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## 'I sensed my GP was beginning to disbelieve me'



### Geraldine Walsh

In part two of a series on hereditary conditions, Amanda Byrne recalls receiving an official diagnosis of Ankylosing Spondylitis five years after the pain began

tion," says Amanda who documents her journey with AS on Instagram. "As the months went on and nothing seemed to be working, I sensed my GP was beginning to disbelieve me. I ended up in A&E three times. The last time the doctor told my husband to take me to see a psychiatrist as I was in no pain, and it was all in my head. Instead, I went to see a chiropractor who asked me about family history, and I mentioned that my dad had AS and he suspected I too had the condition. However, when I spoke to my GP, they dismissed it and fobbed me off to the pain management clinic in St Vincent's hospital."

This was not a solution for Amanda, who suffers nocturnal back pain, pain or stiffness which improves with movement, fatigue and exhaustion which were initially dismissed as "depressive episodes". As AS progresses it can cause your spine and sacroiliac joints to fuse which can result in total fusion of the spine also known as "bamboo spine". Additional symptoms include swelling of different joints, bowel issues, eye inflammation, compression fractures, and heart and breathing problems.

It is not known what causes AS, yet genetic factors seem to play a significant part in developing the condition. Those with the HLA-B27 gene are likely to be at increased risk, however, not everyone with this gene will see AS progress. There is also no cure for AS and it is not possible to reverse the damage caused.

#### Family history

Amanda finally received an official diagnosis five years after the pain began. She attended the sports clinic in Santry, Dublin, and brought a file containing as much information as possible, including bloods. It was here the doctor asked all the right questions and delved into her family history. After further bloods and an MRI, the inflammation in her body was confirmed as AS and she was referred to a rheumatologist.

Having been through a system that was not overtly cognisant of her symptoms or condition, Amanda recommends that if you are the heir to a chronic illness to educate yourself about it. "If you already sus-

pect you have something and are not being listened to by medical professionals, get a second opinion, a third if needed. Advocate for yourself. My biggest regret was believing medical professionals who made assumptions about me. Never again will I allow that to happen."

Dr Fergus Glynn, GP with webdoctor.ie, Ireland's leading online GP service founded by healthcare and IT professionals, advises that all types of arthritis, including the commonest form of arthritis, osteoarthritis ("wear and tear") have hereditary potential, though some more significantly so than others.

"Why arthritis develops in a particular individual is felt to be the result of the interplay between genetic and environmental

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**If you already suspect you have something and are not being listened to by medical professionals, get a second opinion, a third if needed**

factors," says Dr Glynn. "In other words, you need to carry one or more of the many gene markers associated with the disease, but the disease will only express itself as a result of certain environmental exposures, often sustained over long periods, such as stress. Therefore, even if you have a parent or a sibling with a severe form of inflammatory arthritis, for example, rheumatoid arthritis, the likelihood of you developing arthritis is very far from inevitable."

The risk of developing a form of arthritis will vary from individual to individual. However, as Dr Glynn says, even in the case of the commonest inflammatory arthritis, rheumatoid arthritis (RA), if you have a parent (or sibling) with RA, the risk of developing the condition is approximately 60 per cent higher than the general

■ Amanda Byrne: 'My biggest regret was believing medical professionals who made assumptions about me'

population. "Which does admittedly sound alarming," says Dr Glynn, "however, when one considers that the lifetime risk of developing RA is roughly 3.6 per cent in women and 1.7 per cent in men, one still has a far greater likelihood of avoiding this type of arthritis than developing it. And this again speaks to the significant interplay between a host of genetic and environmental factors before RA becomes manifest in a particular individual."

#### Delayed diagnosis

Early diagnosis is the best means of ensuring a positive outcome and preventing the many negative sequelae of delayed diagnosis.

"Consequently," says Dr Glynn, "if there is a history of arthritis within your immediate family and you are experiencing new, unexplained and persisting symptoms suggestive of arthritis, for example, joint pain and or swelling, stiffness, particularly stiffness in the morning upon waking, then it is essential to attend your GP as a matter of urgency. Your GP will undertake a thorough physical examination and order further investigations such as bloods and imaging as appropriate and can refer onwards to a rheumatologist.

"Early diagnosis can, in many instances, especially with the range of advanced therapeutics available today, prevent the severe and disfiguring joint damage that in the past was associated with inflammatory arthritis and which today patients rarely if ever have to endure. In fact, the majority of our patients with arthritis lead perfectly normal lives unhindered by pain or stiffness or loss of joint function so effective are many of the currently available arthritis treatments.

"Physiotherapy and indeed in some instances occupational therapy have crucial roles in optimising the patient experience and outcomes as part of the now established multidisciplinary approach to arthritis treatment."

## 'I'm sorry, I forgot you were my daughter'

### Anthea Rowan

Living with dementia in a loved one is often compared to grief as bits of a life lived together are peeled away and lost

The first time my mother forgot who I was, who I am, came out of nowhere. At breakfast time, as she sat across the table from me with her tea and toast, she knew I was her daughter. By evening, it had gone: something had apparently cut clean through our relationship, like scissors shearing silently through silk.

Remind me, she said, leaning into our conversation, "because I don't remember exactly: When did we first meet?"

I thought she was joking. I reacted as if she was; I laughed. Then I saw her face; it was plain she wasn't. And I wasn't sure who was more shocked. Or what was more shocking to her: that she had forgotten I was her daughter. Or that I was.

Afterwards, as I tried to make sense of it all, I wondered when the memory lapses my siblings and I dismissed affectionately as "forgetful" had slid sinistinely towards clinical.

It's easy to blame so much on senior moments: *She's old. She's tired. Perhaps she's dehydrated*, and I nudge a glass of water in mum's direction.

But forgetting the names of some of the places you've lived, forgetting the names of which grandchild belongs to which of your children, is quite different to forgetting who those children are.

I reeled afterwards. When your mother forgets you, it's as if roots have been pulled up and shaken loose. If your mother doesn't know you, who are you? If your mother has carved you out of her past, what's your history. To know and love a face plays a fundamental role in human connection. Suddenly my mother didn't know mine.

Why do you think I call you mum, I asked, hoping common sense might jog the memory?

She considered my question for a nanosecond: "I thought you were just being polite."

I spent hours then, curating a collection of photographs, pictorial evidence of who I was to her and her parents and her siblings as if I must provide layer upon layer of proof of our kinship. And then I tailed her, laptop open to my pitiful PowerPoint: "See, there's me and you, mum. And here's me and you and your mum. And me and you and my dad, your husband". Me, me, me. Me and you, mum.

She wasn't convinced. I hear her on the phone with her sister, her forgetting has bloomed in proportion to my desperation as indignant resistance: *Who is this woman anyway?*

My eldest daughter, concerned at my distress, asked me how it felt.

It did not feel the same as my father's death. But it felt similar. A separation. I didn't yet understand - I will learn, later - that living with dementia in a loved one is often compared to grief as bits of a life lived together are

peeled away and lost. And it felt alienating: when dad died we were in it together. This seemed selective: why had my mother forgotten me, not my brother or sister?

Later - for there are many things that come later as I play catch up in my understanding of dementia - I will learn that dementia interferes not just with memory but also with the brain's ability to comprehend what the eyes see. It compromises our uniquely human high-level visual processing: a person with dementia can look into the face of a loved one - a daughter - and fail to recognise those intimately familiar features. My mother knew she had a child by my name. She just didn't believe I was her. "You look too old," she insisted, "you look even older than me". I felt like an abstract of myself.

Eventually - even more cruelly - this face blindness might extend to sufferers themselves so that they don't recognise the reflection that stares back at them from a mirror.

Why so sudden though? Why did Mum know me one minute and not the next? In her beautiful memoir, *Keeper: A Book About Memory, Identity, Isolation, Wordsworth and Cake*, which describes her mother-in-law's dementia, Andrea Gillies writes, "there is change afoot and changes come as steps and not as

66 **When your mother forgets you, it's as if roots have been pulled up and shaken loose. If your mother doesn't know you, who are you?**

slopes. There are sudden downward movements'. I have learned she is right. The decline into dementia is not a gradual slide downhill. It is jarring. Breathtaking. It's not even always downhill: sometimes you are jolted hopefully back to the surface.

Two years after that first occasion, my mother has forgotten I am her daughter and then remembered exactly the person I am to her countless times. The first time was just a few weeks later and coincided with my birthday. She wished me happy birthday belatedly; my brother reminded her.

"Thanks mum," I say. Sheepish, "I'm sorry I forgot you were my daughter".

She delivers it in the same tone you might adopt to apologise for something unexceptional: "Sorry I forgot your birthday," say.

That's okay, mum. It wasn't. Not back then. But it is now; now I understand that her forgetting is pathological, never personal.

Today, when she needs reminding of who it is on Skype as she holds her iPad aloft, my brother or sister on speaker phone, I remind her which of my siblings has called, and who they are to her, to me. Then I giggle and say loudly enough, so that whichever sibling is on the other end of the line will hear and laughingly protest, "but I'm your eldest, ma, and I'm your favourite, don't ever forget that: I'm your favourite".

And mum laughs too.



■ Why did Mum know me one minute and not the next?