Edited by: Damian Cullen

Dr Muiris Houston



Forget Chrishaps time and take joy in some hedonism

o, how are you feeling today? A little queasy from too much festive food and drink? Or perhaps feeling a tad virtuous having avoided temptation and even managed some Yuletide

Christmas is a time when medical research loosens the chains of propriety a little. Over the years, the British Medical Journal has published numerous daft and

quirky papers, including an assessment of whether James Bond's drinks were shaken (and not stirred) because he suffered with alcohol-induced tremor and the somewhat startling finding that patients who undergo surgery on the surgeon's birthday experience higher mortality compared with patients who undergo surgery on other days of the year But all is not sweetness and light in the

land of the festive medical journal. The Australian and New Zealand Journal of Public Health has published a paper from German, Dutch and Swiss researchers whose stated aim was "to systematically collect scientific evidence of adverse health effects associated with Christmas in terms of hazards to which we refer as 'Chrishaps' [we expressly mean not only injuries from accidents or falls, but also threats to health from other risks such as high-fat foods or allergenic substances]"

This stern "mittel Europe" literature review revealed various hazards. Allergic reactions were demonstrated to Poinsettia or Euphorbia pulcherrima Willd (a popular Christmas plant), Christmas trees and candles. Poinsettia and holly can lead to contact dermatitis. Not unexpectedly, swallowing and aspiration of Christmas decorations featured: including a Christ-mas tree LED light bulb, confetti stars, button batteries and a plastic robin.

Even more astonishing was a case report of suspected cyanosis in an 18 year old, induced by skin staining from blue bed linen given as a Christmas gift. Reassuringly, however, the authors found no reports that either Santa Claus himself or one of his reindeers were involved in



This is a time of year to loosen any dietary shackles. We all need a week when we can switch off and indulge ourselves

Hopefully your decorating exploits are behind you for another year but the researchers note that "when decorating,

there is a risk of falling, for example, when putting up residential Christmas lights or decorating the house. Among these risks, falls from ladders or roofs were the most common, but also from furniture, with some significant injuries like lacerations, strains and sprains, or fractures.

In terms of dietary risk, the traditional Christmas pudding "must be appreciated as a potential health hazard" due to the alcohol and ethyl carbamate it contains (especially when doused in brandy and set

alight).
"Overeating, to our surprise, has been rarely identified as a Chrishap in our systematic literature search. However, a positive correlation between Christmas and higher cholesterol values was report-

Two other risks from festive eating emerged from the literature review: abdominal pain after eating an entire packet of mints without chewing (in fairness, the man affected was edentulous) and eating a piece of Christmas cake containing a plastic robin. And don't overdo the turkey consumption: a single case finding of higher-pitched voices in

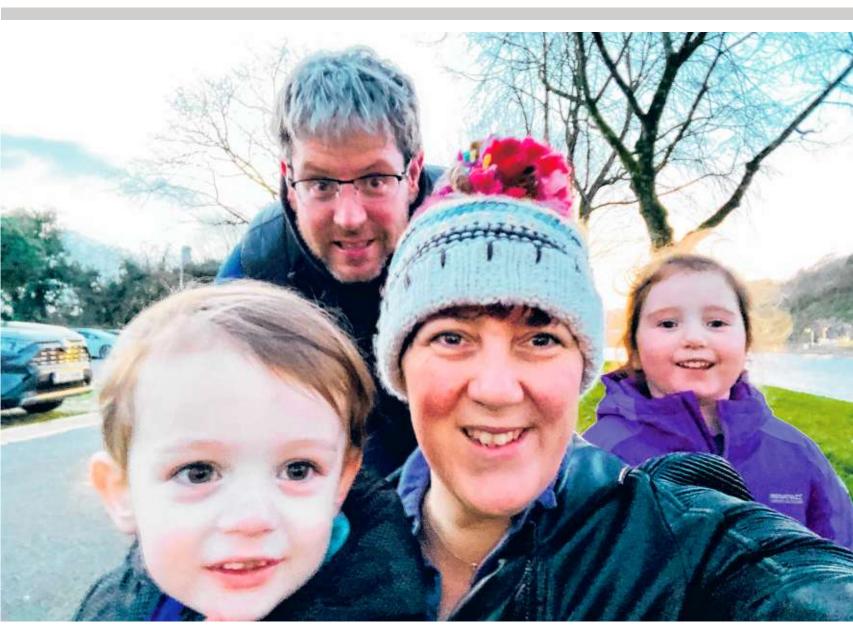
men and a decrease in female pregnancies due to hormones in battery turkeys warns of this bizarre but unlikely outcome.

In what I hope (but cannot be certain) is a tongue-in-cheek conclusion, the authors write: "Given the potential hazards and Chrishaps documented, implications for public health may need to be explored to reduce such risks. To assess and discuss specific public health implications of Chrishaps, higher level studies are needed along with targeted injury surveillance. Overall, further research and effective information may limit Chrishaps and ensure we have a safe and merry Christ-

My advice? Forget about Chrishaps. This is a time of year to loosen any dietary shackles. We all need a week when we can switch off and indulge ourselves. While the calorie count will rise - latest estimates for Christmas dinner is that we consume 6,000 calories during this meal alone letting go for a few days should release additional endorphins and mood-enhancing neurotransmitters that will boost your immune system.

Hedonism has its place. And if not this week, when?

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Deep brain stimulation surgery proves to be a life-changer

Sylvia Thompson

Diagnosed with Parkinson's disease at just 31, a revolutionary new technique has transformed Ivan O'Regan's life

Parkinson's disease is usually seen as a disease of old age, but there are a significant number of younger people diagnosed with it. Diagnosed with early onset Parkinson's at aged 31, Ivan O'Regan was particularly young to have the condition.

"I was an accountant and on the computer all the time," says Ivan, who is now 42. "I began to notice that I had trouble cutting and pasting text with my left hand. I also found that I was holding my left arm into my chest. I went to my GP. He knew straight away what it was, but he didn't tell me at first. He sent me to a neurologist who told me I had Parkinson's.

Ivan started on low-dose medication in tablet form which had to be increased as the condition progressed.

"I never really had a shake. It was a stiffness and slowness of movement down my left side. I had a bar on the side of the bed that I'd use to pull myself out of the bed. I spent long periods of time sitting in a chair," he explains. Stiffness and cramping in muscles and limbs - as opposed to a shake or cognitive decline – are the early symptom most often seen in younger people with Parkinson's

To try to alleviate his symptoms further, Ivan began to use an apomorphine pump which distributes an even dose of dopamine (the chemical whose absence causes Parkinson's symptoms) throughout the day. And while the pump allowed the medication to be absorbed into his blood stream better than the tablet form, it often made him nauseous. This side effect was so disruptive that Ivan began using the pump

less consistently. In 2017, Ivan and Eleanor's daughter Effv was born, and when it was time for Eleanor to go back to work, Ivan took time off work to look after her. In 2018, their son, El-

lis was born. During this time, Ivan's Parkinson's symptoms worsened and he was unable to return to work.

"Parkinson's had progressed faster than we had been expecting. Ivan signed up for the Duodopa pump, but the HSE had taken it off the market at that time," explains El-

The Duodopa pump delivers a synthetic form of dopamine (levadopa) - as well another active ingredient (carbiodopa) to reduce the side effects of the levadopa through a tube into the abdomen. During a two-year period while the HSE negotiated the price with pharmaceutical company AbbVie, the medicine was denied to Irish

Eleanor recalls how not being able to have this medicine was a big setback for the couple. "The medication problems were putting a strain on our relationship and on Ivan's mental health. We had also started talking about Ivan getting deep brain stimulation surgery in the UK, but, once Covid hit, the hospital in London stopped taking patients from Ireland."

Prof Richard Walsh, consultant neurologist at the Mater Hospital in Dublin says hat deep brain stimulation has been "the gold standard treatment for advanced Parkinson's disease and some related movement disorders for over 25 years". During surgery, electrodes are placed in the brain. These electrodes emit an electrical current to circuits within the brain which then regulate abnormal movements in the body.

Invasive surgery

In 2021, Ivan began to pursue the possibility of having deep brain stimulation surgery in Ireland, as consultant neurosurgeon Catherine Moran moved to Beaumont Hospital to initiative the surgical procedure

Before he could be put on a list for surery, Ivan had to go to the Mater Hospital Dublin for a pre-operative assessment. Pre-operative assessments are crucial to working out which patients are most suita ble for this very invasive surgery.

They include the levadopa challenge, which tests the patient's responsiveness to high levels of medication, cognitive tests to check mental capacity and physiotherapy checks if patients are physically fit enough

for the surgery. "Deep brain stimulation doesn't work

for everyone with Parkinson's. Speech and balance don't get better with deep brain stimulation. The surgery improves the abnormal movement that the majority of people with Parkinson's have. It also works very well for patients with a bad tremor,'

explains Moran.

Following his assessment, Ivan was confirmed as a suitable candidate for deep brain stimulation. And less than one year later, he was called for pre-operative MRI scans. In February 2022, he became one of the first patients in Ireland to have deep brain stimulation surgery. "I couldn't wait for it at that stage. The day I had surgery, I wasn't nervous at all. It was like – get me in there," says Ivan.

Five weeks passed before the device could be switched on by Prof Walsh, giving Ivan time to recover from surgery. "The first time Prof Walsh turned it on. I reacted very well. Initially, the device is calibrated every four to six weeks, and then I go for checkups every six months," he explains.

Ivan says that life has been transformed since his surgery. "Effy started school this year and Ellis goes to pre-school. We wouldn't have been able to manage without the surgery. I pick them up from school

Ivan, who looks after the couple's two children during the day, is also confident enough to have their friends visit since having the surgery. Another big benefit is that he sleeps much better. Previously, he only slept three to four hours at night, which also disrupted Eleanor's sleep.

Eleanor says that the surgery has made a huge difference to their lives. "We're not looking to scale mountains. We just wanted to get back to living a relatively normal

We're not looking to scale mountains. We just wanted to get back to living a relatively normal life and the surgery has given us that

■ Ivan and Eleanor O'Regan with their children, Ellis and Effy: 'The Parkinson's progressed faster than we had been expecting.'

life and the surgery has given us that." 'We know that it's not a cure, but if Ivan didn't have deep brain stimulation, I'm not sure where we'd be. I certainly wouldn't have been able to be in full-time employment. I'm not even sure that we'd still be a couple or that Ivan would still be with us because of the mental strain of everything.'

The couple, who live just outside Blarney, are involved with the Cork Parkinson's Association. "We're open to people interested in the surgery talking to us privately about it," says Eleanor.

Younger patients

Prof Walsh says that globally, there is a huge shift to offer deep brain stimulation to younger patients with Parkinson's disease. "We would typically have waited until patients were living with Parkinson's for 12-15 years before considering deep brain stimulation as a last resort," he says. "This meant that patients going through surgery had less time to enjoy the benefits of deep brain stimulation before other challenging symptoms such as dementia and falls emerged," he explains.

Now, patients are selected based on the longer-term benefits to their quality of life once they pass the pre-operative assessments mentioned earlier.

Catherine Moran has carried out 23 deep brain stimulation surgeries from when the service began in November, 2021 until the end of December, 2022. Both she and Prof Walsh are calling on the HSE to make more theatre space available for this crucial surgery as demand has increased since it became available in Ireland.

Private patients whose health insurance covers their treatment in the UK are still sent there for treatment, while other patients can wait for over a year to have the surgery in Ireland.

'Our business plan for deep brain stimulation to the HSE in 2020 called for 40 cases a year, but due to theatre capacity, we have only been able to do about 20 cases a year. The population's needs are for 40 a year, and we will always be behind if we only do 20 a year," says Moran.

Life is too short, and unpredictable, so eat your curry chips now

Orla Tinsley

I have to abstain from winter cravings for my kidney-friendly diet but you should dig into what makes you happy

 \P his past week, as the snow landed, I walked past the Embassy Grill and my heart began to race. I knew that the finest curry chips in Dublin lived there, inches away, and I knew this because I grew up with their cousin, Central Grill (aka purveyors of the finest curry chips in Kildare), minutes from my family home. This was the perfect Irish dish for a winter day because a giant plate of fat chips in a sea of curry can cure any conun-

I think it's McDonnells sauce and a sprinkle of magic that they use.

At that moment, I figured that I finally understood something of what smokers feel when they're trying to quit. Since last year, things have changed drastically for me and when it comes to winter cravings, I must abstain.

This is my first Christmas living with diagnosed end-stage kidney disease, which means: changes, I turned to face them through a trial run cooking a Thanksgiving feast for my parents. Beloved dishes modified and tested, I made them accessible and kidney-friendly in preparation for Christmas. I felt ready-to-writemy-recipe-book levels of confidence, but some dishes could not be saved. End-stage kidney disease causes a build-up of normal minerals and fluids in the body, because the kidneys do not work. The body usually secretes waste through our kidneys. But when it comes to chips or, in particular, curry chips, nothing could be done. Their gastronomic glory could not be imitated, replicated or replaced.

Potassium spike

This rings true for pudding and Christmas cake too, which I have to limit to prevent the fruits from causing a catastrophic potassium spike. And then there is phosphate that must be controlled by carefully administered binders so it doesn't build up in the body. Not to mention the turkey sweats are limited this year as my protein comes in carefully proportioned doses. We do hard things because they are necessary and in this past year I have found joy in exploring escape routes, cooking through the feeling of absence my end-stage kidney disease diet has caused. I pose this question to myself often, dwelling in abundance, what ingredients are available to me?

Over time, alternatives to mac and

cheese found their way into my self-made cookbook, alongside chicken pot pie, non-mushroom green-bean casserole and roast potatoes that had been vigorously boiled first to eliminate the problematic potassium and then buffed and crisped under the broiler. It is possible to be satisfied, but it is not easy. The irony is, before this happened, I mostly avoided fast food. I should have eaten more curry chips

McDonald's cheeseburger

They are something I crave in the depths of despair or, in their absence, a fluffed baked potato (also banned). One time I was in hospital in New Ýork and my amazing friend asked whether I would like any good grub brought in. "McDonald's cheeseburger and chips! With a strawberry shake!" I said, far too enthusiastically. Not wanting to overburden the poet who, like me, was a student, I also knew that people often mistake an unexpressed need for an excuse to bring a fruit basket. I was not willing to let that tragedy happen. The golden sun illuminated the Hudson as my friend arrived with the grub and some poems. I unfurled the paper bag

/ We are 66 bombarded with language from the diet industry designed to create deficit instead of abundance

emblazoned with the golden arches and listened to him read.

The bag looked kind of small, but hey, maybe no napkins. Sensing something, my friend stopped sharp, held up his hands and said: "I'm not sure if you like Ruffles or not so I got another kind too." A dark cloud draped over the room and the archives of my internal dictionary scrambled. I realised my fatal mistake. In the US, chips translates to potato chips. As in: a bag of the crispy cold comfort that provides a sad substitute for a skinny bag of fries. Never mind the chunky Central

Grill chips. Life is too short, and unpredictable, so eat your curry chips now. It's especially worth remembering now as we are bombarded with language from the diet industry designed to create deficit instead of abundance. A recipe made famous by Monica and Ross Geller is on my list for today. The Moist Maker, in all its glory, is a Thanksgiving staple from Friends and it goes like this: Take one slice of bread and soak it in gravy. Next, take two more slices of bread and butter them with mayo. Layer with turkey, mashed potatoes, cranberry sauce, stuffing, lettuce and the gravy bread. Repeat. Eat. That's better. I hope you are eating what you love and that you continue that into the new year.

The time is now.



■ The gastronomic glory of curry chips cannot be imitated or replaced

Health #Family

Edited by: Damian Cullen

Muiris Houston



Dr ChatGPT: are robot doctors really the future?

ello, my name is Dr ChatGPT. How can I help you today?" Imagine a medical consultation with a robotic creature. Will you feel comfortable? Will you trust this product of artificial intelligence (AI) to look after you effectively and safely? I'm not sure how far away such a reality is, but it is certainly attracting heavy

investment. The latest version of AI to hit the headlines, ChatGPT, has been creating a stir since the US start-up OpenAI made the text-based dialogue system accessible to the public in November 2022. ChatGPT stands for Chat Generative Pre-trained Transformer.

ChatGPT may be a long way from the AI technology that fuels a functioning robotic

doctor but there is a clear intent that machines will eventually replace human physicians. Those arguing for this eventuality say that deep-learning AI systems continually integrate new knowledge and perfect themselves with a speed that humans cannot match. They also highlight he has fire of wine AI to treet. light the benefits of using AI to treat patients, including increased availability, lower costs and no risk of mutual infec-

Sceptics argue that AI in healthcare is overhyped, profit-driven and not always in patients' best interests. But even if we were to have high-level evidence of the superiority of AI to medical professionals, would that justify replacing humans with

In an editorial in the British Medical Journal Dr Vanessa Rampton says the question asks us to differentiate between the technical prowess of AI and the more fundamental question of whether human physicians can provide something that machines will never be able to.

In my opinion, robot simulated empathy can never replicate human forms of communication. Human doctors can relate to patients as fellow mortals and vulnerable beings. Patients need to be



In my opinion, robot simulated empathy can never replicate human forms of communication. **Human doctors can relate** to patients as fellow mortals and vulnerable beings . . . A machine will never be able to show us true comfort

cared for by people, especially when we are ill and at our most vulnerable. A machine will never be able to show us true

In the intimate crucible of a doctor-patient consultation, there is a need to appreciate patients' values, their non-verbal communications and their social circumstances. These factors become especially important if a patient has symptoms for which no diagnosis can be found or cure is not an option.

Empathetic connection

According to Rampton, patients emphasise that sensing your doctor truly cares about what you are going through, really wants to help and is able to establish a "genuinely intimate and empathetic connection" makes a big difference to their ability to manage their health. Research from Yale University, pub-

lished last year, offers an up-to-date understanding of patients' views of AI in healthcare. Most of the 926 respondents were very concerned or somewhat concerned about AI's unintended conse quences, including misdiagnosis (91.5 per cent), privacy breaches (71 per cent), less time with clinicians (70 per cent), and

higher healthcare costs (68 per cent). Patients acknowledge that AI could help physicians integrate the most recent

THE IRISH TIMES Tuesday, May 2, 2023

scientific evidence into medical care. But there is a strong feeling that AI in medicine should be disclosed and controlled to protect patient interests and meet ethical standards.

In the radiology arena, people seem reasonably relaxed to have diagnostic technology work hand in hand with the radiologist. Recent research shows that AI software can detect TB from chest X-rays at an accuracy level comparable to, or better than, that of the radiologists tested.

AI may have the potential to become a useful and innovative aide in healthcare, but I believe there will always be room for humanity. If digital technologies enable the development of new forms of knowledge and diagnostic accuracy, it would seem foolish not to welcome them. But a key question remains: as technology continues to change relationships between patients and doctors, how can we

maintain an essential trust in the process? Without this bedrock of trust we may need to slow down trends towards more

automation in the consulting room. mhouston@irishtimes.com



'I never felt like my asthma symptoms could improve'



Arlene Harris

After vital intervention, Dublin woman Sarah Darcy was able to reduce her medication for asthma

arah Darcy has had asthma since childhood, though she was only diagnosed as a teenager.

"I was always seen as being 'chesty' as a kid as I was known for terrible coughs," she says.

"But it wasn't till I was a teenager that I was diagnosed with asthma. I remember my chest being very tight and I felt like I was struggling to breathe. "I think my mam might have thought I

was trying to get out of a test in school, which could have been true, to be fair, but she brought me to the doctor, who diagnosed asthma – and I'm not sure which one of us was more surprised. "After that and throughout my teens and

20s, my asthma was always in the background - but I could never be accused of being sporty, so I can't really say that asthma caused issues there. "However, I would have had coughing

was trying to shout over music and background noise on a night out. "I know now that all of those things

fits if I talked for a long time, or laughed, or

meant that my asthma wasn't well con-

The 44-year-old company director says that, although her medication changed over the years, she never really felt "on top" of the condition. For years she was able to "get by", but in 2017 she had a very serious episode, which saw her seeking help from the Asthma Society and getting advice on how to better manage the disease.

"Over time I went from having just a blue reliever inhaler to a reliever and a preventer and then went on to a stronger preventer inhaler (a powder inhaler)," Darcy says.

Asthma is a disease characterised by inflammation of the airways. "Controller inhalers are anti-inflammatory medicines prescribed to prevent the symptoms of asthma from occurring, by reducing the inflammation over time and lowering the risk of an asthma attack," a spokesperson for the Asthma Society says.

"It does not provide any instant relief of symptoms, but builds up protection and reduces symptoms over a longer period.

"Controller inhalers are now considered to be the cornerstone of asthma treatment. according to clinicians and the Global Initiative for Asthma international best practice guidelines on asthma management, while reliever inhalers are prescribed for use when symptoms flare. These work quickly by opening the airways wider and making it easier to breathe again, by relaxing the muscles which tighten when asthma symptoms worsen.

"The majority of people with asthma are prescribed a daily controller inhaler to protect against an asthma attack and a reliever inhaler to use when symptoms occur," the spokesperson says.

"The controller medication should be taken every day, as prescribed and even when asthma symptoms are not present.'

Darcy always felt like the medications she took "were just to keep me at the symptom level I was at – and I never felt like my asthma symptoms could ever improve".

Build-up of symptoms

In Darcy's case, there was a very slow build-up of symptoms, and several courses of oral steroids in a year would not have been unusual for her.

"In 2015, I was referred for testing for the first time, this resulted in me being put on new medication, but I don't remember much follow-up beyond checking whether I needed new prescriptions and I continued to have that slow build-up of symptoms like the cliche of the frog in hot water, I didn't notice how much worse it was getting," Darcy explains.

"Then in 2017, I had a significant asthma attack with constant coughing and blue lips -and I attended the emergency department with it for the first time.

About asthma Figures and triggers



Now I can run for the bus without coughing and other people don't comment about being able to hear me breathe from across the room any more

"Since then, I've attended A&E a few times with asthma attacks, but fortunately I have never had to be admitted to hospital.

"Even more fortunate, when I presented to hospital that first time, the senior registrar had a special interest in respiratory illnesses and recognised that my asthma was

"He referred me to the respiratory clinic

in Connolly Hospital and suggested contact-

Asthma is an inflammatory disease of varying severity that affects the airways. Ireland has among the highest rates of asthmain the world.

Findings of 2019 research suggest one in five (890,000) people have a lifetime prevalence rate, and while there is a one-in-13 annual prevalence rate in adults and a one-in-10 annual prevalence rate in

■ Central Statistics Office figures suggest a fall in death rates since 2015, with 61 deaths in 2016 and 57 deaths in 2017, though these figures remain unacceptably high, in light of asthma

being a largely manageable disease. People with asthma have airways which are extra sensitive to substances (or triggers) which irritate them. Air pollution can severely impact their quality of life by triggering symptoms while studies have shown that air pollution can cause asthmain young children.

According to recent research, reducing air pollution can save lives and better the quality of life for someone with asthma. Common symptoms include coughing, wheezing, shortness of breath, and chest tightness. If anyone has any concerns they should seek advice from their GP.

Reliever inhalers are prescribed for when ashthma symptoms flare. Left: asthma sufferer Sarah Darcy. PHOTOGRAPH: ISTOCK

ing the Asthma Society advice line - and it's not an exaggeration to say that this was life-changing.

The Dublin woman says that following this vital intervention, her asthma is now well controlled and she has been able to reduce the amount of medication she is tak-

ing.
"Knowing my triggers and knowing what good asthma control looks like for me means I can breathe without wheezing all the time," she says.

"At the moment, my job involves some public speaking, where I give presentations to groups of staff for our clients, and present training to groups of administrators.

"This means speaking for anywhere between an hour to over three hours to groups of different sizes, both online and in-person – and there is no way I could manage this if my asthma wasn't well controlled.

"Also, now I can run for the bus without coughing and I've noticed that other people don't comment about being able to hear me breathe from across the room any more. "I can sing along to the radio as well - al-

though not sure other people would agree that's a good thing - but my sleep quality is better too, which makes a huge difference to pretty much everything.

"During the initial call [to the advice line] and the follow-up calls from specialist nurses, we spoke about good inhaler technique, having an asthma management plan, peak flow readings, and how to recognise an asthma attack and this was all so helpful," Darcy

'There are great videos on the Asthma Society website too and knowing how to recognise an asthma attack and the five-step plan for [what to do during] an asthma attack have been so beneficial both to me and my family as it gave all of us a set of guidelines for what to watch out for and helped my family to know what to do in an emergency situation.

"One of the most important things for me is that I now feel like I am better able to advocate for myself when discussing my asthma with healthcare professionals.

"I am armed with more information and a better understanding of my medications. It helps me feel like managing my asthma is a partnership, rather than something which is just happening to me."

Asthma Awareness Week takes place from May 1st-7th. The Asthma Society in Ireland is hosting a virtual informational conference on the topic of Asthma Care for All tomorrow, May 3rd (see asthma.ie)

I stay in the sun seeking something beyond reality as long as I can



In the Irish health service, it is up to the patient to make the space-time continuum between the then of the appointment and the now of the pain work

ow that I am home, I revel in light. When birdsong fills my ears and inspires my body to wake, I am overjoyed by the heat that beams in my window. My cat, Harper, stretches into it as only a cat can, sleek and sun-kissed, but my impression is lacking. When I abandon the sun, it is for colder realities.

I have great thinkers on my team, but no practical progression towards healing the legs. I need some magnets to bounce off my skin, some magnetic field gradients, and some experts to inform and enhance the energy I am currently getting. I am suspended like a trapeze artist mid-flight watching their landing spot disappear. I swing endlessly, focused on the energy I am burning up, and I am getting tired. If I fall it's on me, because I must be my own advocate for air and energy or building any physical therapy beyond the pain.

Outpatient list

It has been almost four months. I've started to accept that maybe the landing strip does not exist – but the art of trapeze comes naturally to me. and I am not interested in giving up until I can find some safe ground. Refuge, I know, is often never external, but the MRI outpatient list is roughly one trip around the sun away and I can't help but notice the clear mark. In the Irish health service, it is up to the patient to make the space-time continuum between the then of the appointment and the now of the pain work.

Of course, the idea that doctors can claim and confirm a timeline for existence and death is only partially true - the best doctors will tell you this - especially in a system that cannot provide what every party needs. Everyone gets burnt. And, at the same time, anything can happen, sure. The difference now, for me, is the arising of physical pain that obliterates hours in its wake and when I wake, whatever time, it may choose to exist or not.

My mind is left to gather and galvanise my body into wakefulness. The internet becomes my best friend

and says yes to possible solutions for rippling and prolonged pain on treatment when my teams cannot provide help. I attend a physio Pilates specialist to supply strength and to stretch the shortened muscles that twist and tighten with each dialysis treatment. These women are a gift because no one else offers anything like this. And it is massage that provides the only pain relief through acupressure - this is also not available to me. I am sure the lack of access frustrates care teams

It is hard to understand why hospitals cannot suggest or provide someone with these skill sets to elevate mobility and provide pain relief, but there is no one and no one is offered. Midair my toes grasp at the reformer bar as I am working to support my body. It is in repeated sequences we build and I breathe.

I add a stick to my repertoire, upon my own advice and consultation, to move through the world. I am reluctant to have any kind of dependency on it and remember everything I learned about how muscles can over- and under-compensate. Or, as my old cystic fibrosis physio would say about training: your body will always try to find the easy way out.

Temporaryfix

With my new temporary fix, I oscillate between long-bearded dancing Fagin vibes and when the sun is shining, I think more about J-Lo in the Get Right Video. I tell myself...just air out the waistcoat! In the meantime, I ring the neurologist again and he moves fast to provide a second opinion. That's how we arrived here, waiting for that MRI the second doctor ordered a

Jessica Fletcher, another icon, taught me some sleuthing skills to get to this self-sufficient point. If I keep investigating, I will unmask the terrible pain terrorising my body and be home for tea and one last laugh with the mysteriously bland police chief, Mort. Even in the most extreme, murderously painful situations, the mundane maintains and the plot-line endures, maybe. Of course, sometimes, the cure is a

Part of my character is that I am a warrior, not a worrier. I stay in the sun seeking something beyond reality as long as I can, sinking and searching with heat in my heart. In the car, on the way to the hospital, the daffodils on the roundabout gather golden and glowing as the sun glitters on the ground. I marvel at their beauty when the driver says: "Ah sure where have you been! They won't be around for much longer.'

The fleeting nature of beauty entrances as his words cut clear and we drive faster along the road. That Edward Hopper painting comes to mind when the sun washes over my ankles and calves and hips.

I hug my knees to nurture all the places I hurt and then I pick up my stick and move into the world.



■ Edward Hopper's 1952 painting Morning Sun

Edited by: Damian Cullen

Pádraig O'Moráin



Do adolescents really view mum and dad as idiots?

re adolescents a stroppy lot who view mum and dad as idiots? That seems to be the general view, if we were to go by the hostile and disapproving adolescents on the thousands of detective series we've all been consuming since the start of the pandem-

In all languages they archly look down their noses at mum or dad – usually dad. Yet, research into teenage-parent relationships shows this is not the whole story. The research is reported in the American Psychological Association's Monitor on Psychology. One intriguing finding in neuroscience research shows that the

pleasure centre of the brain is activated in adolescents if they receive a benefit for themselves or their parents but not for $strangers. \ This \, suggests \, that \, adolescents$ and their parents form a very specific and strong group even when one side despairs of the other.

Maybe it also suggests that they are more canny than they are given credit forthere are a lot of strangers in the world for whom it might not be wise to provide

Adolescents, as we know, have a heightened emotional sensitivity to social interactions, to their place in the group. That applies to a close group of friends or to a much wider group who, for instance, dress in a particular way or follow the same band. It's easy to think of this as peer pressure and a potentially bad thing, leading to risky behaviour and drug use. Peer pressure can work two ways,

It can also work to encourage the teenager into beneficial behaviours such as sports or non-violent social activism for instance. It's worth remembering too that people of every age are subject to peer pressure, though it might be more accu-

I think a lot of parents believe that it's too late – that by adolescence, peers have all the power. But this research is showing that parents shouldn't give up, that they still do have the power to help their adolescents learn how to process and regulate their emotions

rate to call it peer influence. This is why word of mouth is regarded as one of the most effective marketing tools. At all ages, too, we can be influenced by how our friends feel and what they do.

For instance, the friends of a person who gives up smoking are more likely to give up smoking themselves.

If you take the time to think how many of your adult choices have been influenced by word of mouth, you might be surprised. With social interaction, though, comes the possibility of rejection where one is cut

out of the give and take of the group. Research also states that those adolescents who are especially sensitive to rejection are more likely to suffer depression or indeed suicidal thinking later in life. Most, if not all, adolescents are sensitive to rejection but to be especially sensitive to it is truly painful.

This underlines the importance of school mental health programmes, school counselling and good services in the community for adolescents. We are a long way from that now.

Yet, such services could determine the whole future direction of many people's

Images of what is going on in the brain suggest the brain activity of adolescents mirrors that of their parents. It's easy to imagine, especially during the more conflicted periods, that parents or adolescents are two different species but it isn't so. The bond is stronger than it may seem. (These images track the flow of oxygen in the blood which in turn shows which areas of the brain are active.)

If the relationship is going through a stormy patch - which can be long - the information that the activity of his or her brain mirrors that of the parents might not, of course, be welcomed.

Jennifer Silk, professor of psychology at the University of Pittsburgh, says: "I think a lot of parents believe that it's too latethat by adolescence, peers have all the power. But this research is showing that parents shouldn't give up, that they still do have the power to help their adolescents learn how to process and regulate their emotions.

 $Needless \, to \, say, part \, of \, that \, means$ being unpopular with your adolescent as vou set boundaries.

When it's done with love and consistency, however, it's worth it.

Pádraig O'Moráin is accredited by the Irish Association for Counselling and Psychotherapy. His latest book is Acceptance -Create Change and Move Forward

Did you know the term 'grief overload' exists?



Gabrielle Cummins

Having experienced the bereavement of so many family members before I'd turned 45, the term resonates

don't think I ever saw my sister Geraldine wear all black. It seemed appropriate, then, that we asked everyone at-Ltending her funeral to wear "a pop of

In March 2022, Geraldine died unexpectedly, aged 58. She left behind three heartbroken adult children and us, her nine remaining siblings. I am the youngest of 12 children and this year I have been struggling to navigate yet another traumatic loss.
In 2003, my brother Fintan died by sui-

cide. Two years later my father was diagnosed with oesophageal cancer and died from the illness in 2011. My parents used to always say, "We came into the world nine months apart." A mere 11 months separated their exit, as our mother died from vascular dementia in November 2012.

After two decades of living with debilitating stroke damage, my father-in-law died peacefully in the summer of 2014, just four weeks before the birth of our second child. The many stories shared by my mother-in-law, my husband and Paddy's two other sons have given me a vivid sense of a quiet but strong man. The grief that emerged around his death echoed the grief my family had experienced when my mother died; a sadness for the much-loved man who had just departed and a lament for the man I had never had the chance to know, prior to

In October 2016, my sister's husband Jan died suddenly aged 55. A talented master jeweller from Armenia, he had stolen Imelda's heart in the 1990s. They set up home and a thriving business in the quiet suburbs of Williamsburg, Virginia, in the United States where they lovingly raised their son, my nephew Jonathan.

From my teenage years and into adulthood, many of my life's milestones had been commemorated with a unique piece of jewellery designed by Jan. When a robbery occurred at our home during Christmas 2015, all that treasured jewellery was stolen. In tears, I called Jan. Without hesitation, he meticulously recreated the magnificent engagement and wedding rings that he had produced for my wedding day. After being spoiled with jewellery gifts crafted by Jan since I was a teenager, little did I know that these rings would be the last he would create for me.

Another shocking and traumatic death followed in June 2018. My eldest brother, TJ, who had become paraplegic after a tragic accident, died from subsequent complications. He was 61.

Solace

With each family death, I've found solace through writing and listening to others' experiences. Sadly, there's always someone who can relate. There is comfort in num-

Did you know the term "grief overload" exists? I had never heard of it until this year. Having experienced the bereavement of so many family members before I'd turned 45. the term resonates. Respected author on the topic of healing in grief, Alan Wolfelt from the American Centre for Loss in Colorado, describes it as "different from typical grief ... when dealing with multiple losses, the grief often seems especially chaotic and

defeating". My brother Fintan died on March 19th, 2003, so his 20th anniversary and my sister's first anniversary are days apart. I dread both. Since Fintan's death, I had professed many times that no other death would be as horrific because losing Fintan was my first family bereavement, and it was such a traumatic shock. He was 31 when he



chose to end his life and I was 26. His suicide left such a deep and lingering scar that I can still recall the minutiae of details from that time. As his only younger sibling, Fintan had always tried his best to look out for his little sister.

Almost two decades on, the pain had somewhat healed but I knew, if triggered, that the initial scar had the potential to burst and expose the rawness I'd experi enced years ago. My sister Geraldine's sudden death has brought about a new depth of grief, with which I am still grappling. Counselling has helped me in the past and I have

no doubt it will again; when I'm ready. As a stereotypical poet, Geraldine loved nature and the wild. She chose to live on her own in a remote part of Co Mayo. Throughout her life, she was heavily involved in the community and was loved by many kindred spirits who crossed her path. As an introverted extrovert who also had a complicated relationship with family, Geraldine opted for a solitary existence. She and I had allowed many years to pass without speaking. Today, I am grateful we had reconciled, sparing me from what I'm sure would have been another layer of complicated grief.

In the days preceding Geraldine's death, a few of us had been in touch with her, but when she failed to show up at a friend's wedding and her mobile remained unanswered, the alarm was immediately raised.

Gardaí quickly ruled out foul play and indicated natural causes, but it took months for the exact outcome to be known. The coroner's office in Mayo had initially projected that postmortem results would "likely be furnished within a few weeks". Those proiections were extended to 12 weeks. The reality was 16 weeks. Why such a delay? The relentless battle for answers makes any unexpected death more difficult for an already spent, grieving family. That gut-wrenching imbo land" is like a living purgatory.

Answers help. In July 2022, we were told that Geraldine had died from an aortic aneurysm, that her death was estimated to have been quick and that it most likely occurred the day she was found. This much fought-for clarity provid-

ed enormous relief. For me, it felt like permission had finally

been given to move to another stage of

Stages of grief unfold uniquely for each person. No two people will grieve the same way. I have always found comfort in talking and sharing. This is not for everyone. It helps to be aware that each person's path through grief deserves mutual and individual respect.

'Letter of wishes'

A "letter of wishes" is not often talked about but if written in advance by the deceased, it can provide a grieving family with important tools such as specific funeral wishes or, for example, if you leave young children behind, it can cover details about how you would like them to be educated or their religion. It is a document that can be drafted to accompany the will, to provide helpful guidance to the executors, trustees and/or family members dealing with your estate. It is not legally binding, can be confidential and easily changed or reviewed.

Geraldine didn't have a letter of wishes but unsurprisingly, due to our more frequent brushes with bereavement than most other families, we had conversations about death so we were relatively confident that she would have wanted a humanist ceremony and to be cremated. Armed with this 'comforting" knowledge, we worked together to give Geraldine the personal and neartfelt send-off she deserved.

The staff at Shannon Crematorium sensitively guided us through this difficult process and respectfully allowed us the freedom to personalise the ceremony. We wanted the gathering to be more about celebrating Geraldine's life in a joyous, creative way rather than mournfully lamenting her death. We believe this is what Geraldine would have wanted.

Art, be it music, song, written word or any other form, brings people together when they need it most. Geraldine's oldest son, Shane, read a poignant poem at the ceremony that she had penned called Focal Ghrá. This was from her debut collection of works, published 25 years previously. With every line that Shane emotionally recited aloud, as Gaeilge, I could see Geraldine's face. It was a vivid and happy memory from November 1997. On that day, Geraldine had been bursting with pride, as then constituent minister for environment Noel Dempsey had launched her book, Darkness and Light, in Maguires at the foot of the Hill of Tara in Co Meath. As Geraldine's words, through her son, filled the room, I felt comforted.

Geraldine's second son, Gearóid, bravely volunteered to be master of ceremonies. His sharp wit ensured all of us who were gathered, either on site or online, shared a few laughs between our many tears. Geraldine's youngest child and only daughter, Megan, is an actor and singer. In 2021, a reviewer in this paper described Megan as "destined to be a huge star" and her proud Mam had shared that review far and wide. Poignantly, just months before Geraldine died, Megan had written and performed a song about her mother, which she had recorded and given to her as a unique Christmas gift, the last gift she would give to her Mam. In a fitting tribute, that same song formed the soundtrack for the photo montage of Geraldine's life that we shared at the ceremony. It was a goosebump moment that was both devastating and comforting.

As the ceremony drew to a close, Thurles band (and lifelong friends of Geraldine) The Infantinis performed The Weight (by Canadian-American ensemble The Band). The eerily apt lyrics "take a load off [Fanny] and you put the load right on me" soulfully accompanied the coffin to its final destination. Reflecting one year on, I am optimistic that all who joined us on that sun-filled March day in 2022 left the crematorium feeling both uplifted and sad. It was a bittersweet goodbye.

As more of us live longer, struggles with grief will inevitably occur more frequently. Grief expert Dr Wolfelt offers this advice for anyone experiencing the darkness of those first 365 days of grief: "Over time and through active mourning, they come through and so will you.

I plan to climb Geraldine's much-loved Hill of Tara, where I will read her poetry, sing some of her favourite ballads and feel

her presence. For now, that sense of hope will have to

'I have been in earth-shattering pain for three weeks'



In my 35 years, I've felt the ecstasy of miracle through my bones and have gloried in the glow of rebirth

have been in earth-shattering pain for three weeks and I have been in hospital for one. What I mean by earth-shattering is that my earth, the ground beneath my feet, breaks into a million little shards and spikes into my skin, causing sharp consistent pain when moving. It's in my calves when I'm walking and when being dialysed.

None of my consultants can say why it is happening. The pain relief being offered does not work. After dialysis, a lifesaving treatment that I must have three times a week or by the end of that week I will go into a coma and die, I pay cold hard cash from my depleting bank account to travel to my local acupuncture

It is not as available in Ireland as it was in Manhattan, but I am grateful that it is available at all. My doctor arrived from Mongolia less than a year ago and he can do with his hands what our medical system does not offer and what morphine cannot fix. After the massage, I have two to three hours of relative freedom before the pain starts and builds again, layers and layers cementing each foundation with a terrible weight.

I drag my body. No one knows why. It began after a drug I was given in January and when I was a child I had very bad experiences with it but no one can remember exactly what these were. Since I was a child, neither do I. It should be enough, but it is not. My team want the drug to continue. This is sometimes how post-transplant life is, in that you do the things you do not want to do for the greater good of longevity or quality of life. When you make the informed decision to go on a transplant journeyalthough there is little choice but deaththese are understood bonds.

It is hard to accept when there are no answers. After one week. I demand a change - better pain relief and something verifiable that qualifies what is happening. No one can give it and they are trying, hard. I wait two days for a bed and I cannot dialyse properly, which will kill me faster than anything else if we continue without it.

I push for care. I cry in pain.

Sharp and unrelenting

I've to tolerate the treatment for as long as possible to stay alive but no one can relieve the pain that builds the longer I'm on dialysis. After two days of morphine, the pain stops. The pain is a full-bodied contraction in the lower limbs. It is sharp and unrelenting. I am living in a windowless room in the Mater trying to solve this. On the second weekend, we decide to break up the treatment. I am grateful. Three hours on two consecutive days of dialysis to flush out the system in short bursts. The thought is that this would be less painful – not four hours. On the first day, the nurse set me up for four hours.

Surely, this is a mistake. After two days of morphine and a clear indication from the team what was arranged, it shouldn't be for four hours. It drags on with no confirmation and, since we are adding an antibiotic into the mix, I have to stay on for an extra 30 minutes while they order the antibiotic and get it from the pharmacy. They tell me about the antibiotic that is not yet ready. These things happen. The extra time makes me nervous but maybe I am cured, I think, because the pain has stopped. Thank goodness for whatever has happened. We have done something right. Morphine or time,

maybe. Team work is the dream work! The next morning, I am told the second three hours of dialysis treatment is two hours of iso (isolated ultrafiltration). This is not a dialysis treatment but a removal of fluid. Only excess fluid is extracted from the blood and a full dialysis does not happen. I am certain the prescription was: three hours of full dialysis on Friday and three hours of full dialysis on Saturday. That morning, the nurse said I am set for two hours of iso. I confirm this is not the prescription. It goes back and forth, I give up, shrug. They must be right.

I turn on Joan Jett. With 28 minutes left, I am halfway through Bad Reputation when a nurse walks in to tell me the doctor wants four hours of dialysis so we will need to add two to the two I am already on. But, I say, I am not on dialysis, I am on iso. No, you are on dialysis, she says. The machine reveals what is programmed: iso. The next day, the consultant confirms my understanding of the prescription to be the correct one.

What went wrong? It is something to do with communication, with translation, that I cannot work out. So often things go right, but often things go wrong.

As a patient, it is upsetting – my life is in their hands. As an activist, it is frustrating - my voice is not just mine, it is those who came before me and who are gone and who will come after me. And as a writer - sentences run at me daily and whether I have the energy enough to Should I even speak this out loud? I do because, after six years living in the heart of it, I am still a New Yorker. And before all of that, I am me.

Days before my admission, I delivered the 30th Carmichael Lecture at the Royal College of Surgeons. It is one of the honours of my life to address the past, present and future of Irish medicine. I had been in this unexplainable pain for six days by the time the day arrived and I did not want to represent the miracle of transplant on such an important stage without being fully in control of my body. I go virtual.

The talk is about how to make things better. I think of it a lot while in a room with no view to the outside world for five weeks. It's a negative pressure room for people with infectious diseases which I do not have. There are four of these on the transplant unit and I cannot imagine recovering from transplant in one. I don't need to medically be in this room and there are other people on the ward who do. It feels like a punishment, like a cruelty, although these rooms are doled out arbitrarily, I am told. Of course, no one wants to be in them. The Bat Cave, I call it, because attitude helps.

After the last hot meal around 4.30pm, everything quietens down on the ward, but it makes no difference to me, in the room nothing from the outside can be heard. There is a small window that looks on to the nurses' station and, beyond that, the light from the outside shines through another patient's room opposite mine. I can see the outside. three windows deep.

A patient raised funds for light installations to make rooms more bearable – what a genius idea. This is a hero at work. My understanding is that the Mater chiefs saw a mock-up of these rooms with the installations late last year.

So, I wonder, why has nothing changed? The challenges of darkness are many fold and, in some ways, these five weeks have been a learning experience. I've had to sit with myself, with the reality of the situation and the unreality of the inhumane room. It has solidified my gratitude, but it has also made me angry and irrational. It has delayed my ability to heal because I could not see the sky.

But this was unlike the last time they put me in one of these rooms. Back then, I was in sudden end-stage kidney failure and could not move. At least now, I can get up and walk around, but not much. As anyone with a chronic illness knows, hospital is not a holiday, it's more of a gladiator match. Renal: ready! Transplant: ready! Neuro: ready!

Who knows who will walk through the door next. You have to be in the room. The installations were needed yesterday. The money is there, the company is there and the specs have been delivered. Let's get it done. We can make it better.