

Reader Magazine

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EDITORIAL

Out of nothing...



...**was our universe created.** So goes the current scientific nonsense. Arrogant certainty in influential parts of the scientific community has a good pedigree when it is dealing with the public, “we’re scientists and therefore you lot must accept what we say as true”. So it was with such things as; of course the earth is flat, all you have to do is observe it to know it is so, how dare you say that the sun doesn’t go round the earth, such a thing flies in the face of reason and observation, fire is the result of flogiston, and element that exists in things that burn such as wood and coal but not in others that refuse to ignite such as stone and metal, human beings were created as such from the beginning, gold can be made from base metals [eventually, once we know how]...and so on. Certain scientists who stoutly deny the existence of any sort of divine involvement in creation boldly arrive at the conclusion that our universe was the result of a Big Bang before which there was nothing and certainly no god. Yet they leave us poor non-scientists wondering if, as they say, there was nothing, what exactly was it that went Bang?

Now, at last, after many hours of deep reflection in the hallowed precincts of the Flag and Bottle, and after sustaining myself with draughts of brain-empowering stimulant, I can reveal the truth as I first tried to express it to Daphne, our charming and erudite barmaid...there *was* Something there. However, that fertile Something from which everything would subsequently derive and evolve, with or without a Bang, existed neither in space nor in time, invisible, unmeasurable but nonetheless there.

What is it that can be so profound, prolific and powerful to create a universe?

Possibilities.

Possibilities take up no space and don't involve time. The Nothing of our scientists is, in fact, all the possibilities that may arise if operated on by time. Time is the Bang element. Time, with nothing to operate does not "exist" it is, itself, perhaps only a possibility [*I haven't settled on any definite decision yet but I'm working on it*]. But, somehow [*yes, I know, but I'm working on it*] time interacted with one of the possibilities, time when allied to a possibility created a probability and any probability, given enough time, must become a reality! Certainly, there was no shortage of time, there was literally all the time in the world, so I suppose the probability phase lasted something less than an instant before we had our first reality – that would have made a bang, a Big Bang. Suddenly the driving energy of our universe, Time, had something to work on, something that existed in space, or maybe the first reality was space [*not outer space, but the business of occupying a physical point, the idea of "being"*]. Once there was one reality others became involved and somehow [*watch out for this word, it'll be used a lot*] interacted one with another to create an explosion of probabilities driven by time to become an expanding universe of new probabilities and new realities for, of course the supply of possibilities was limitless....and that's as far as I've got.

Maybe Daphne can help me make progress, unfortunately I will have to throw my great scientific opus on her mercy and ask for credit. I'll let you know how it works out.

Jim Green



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Family Ties Go Beyond Token Gestures

“A cord of three strands is not quickly broken.”

Fiona Lindsay

A winter wedding is always fun. For Jessica and Luke, as teenage sweethearts, their first love tokens were friendship bracelets. Seven years later, a solitaire diamond engagement ring shows their relationship is serious. Soon, the sparkle from frosted holly berries promises to illuminate their fabulous occasion. Questions about getting to the church on a sledge are amusing, at first. During their pre-wedding chat, when the vicar explains that the purpose of marriage is the covenant union of a man and a woman to commit to each other, Luke gets the jitters. Both are quiet on the drive home. The hall mirror reflects a pale complexion next to Luke's olive tones to remind Jessica to book hair highlights. When the groom produces the itinerary clarifying wedding plans, he liberally adds “weather permitting.”

Despite earlier parental involvement, the bride worries her family are adding many of their own ideas. The couple must confirm arrangements with caterers, necessitating firm decisions. Once plans are agreed, her groom can tackle his family because being bombarded with questions from either side warrants a united front.

‘Don't forget to mention we're serving a nip of sloe gin as an alternative to tea and coffee at the church,’ Luke says.

‘Thanks! I'll leave that update to you.’

‘We can do this! After all, it's not quite the when Harry met Meghan wedding.’

Next day, after an early shift she broaches her parents showing them the top table plan. A high pitched, ‘Who's sitting there, exactly?’ comes from Mum.

‘Actually, it's a place for your granddad,’ the bride points towards Dad, who's called Henry. She winks at him. ‘At least, it's space for Great-Granddad's notebook, so he's there in spirit.’ She recalls the quirky notebook contents.

'What a lovely sentiment but you're joking?' Mum pushes her plate away to pace the kitchen. 'You've instigated a memory seat when the wedding breakfast is already oversubscribed?'

Henry strolls back from the lounge where he retrieves his grandfather's, nineteen-twenty notebook of tips for life, complete with business anecdotes. 'Now let's not forget absent relatives, shall we?' He places the leather-bound book open on the kitchen table in front of him to read from "Tom." Dad reminisces using a posh voice, "'I have always made something, and there has been no greater joy or finer sport than being the creator of something...I hope this small treasure will help you.'" He looks up from concerns penned years ago for Henry's father, as a sick infant. This inherited advice can bless Jessica as she exchanges wedding bands.

'Don't be dramatic!' Mum switches off the radio carols.

Jessica longs for Dad to take her down the aisle in his new suit. This reassurance is welcome a month before she changes surname.

Dad indulges, 'Listen, "I hope you will have a wider outlook on life- get learning, get wisdom, culture."'

'Tick, Jess already has them! Traditionally you toast absent friends in your speech, love. Let's avoid any controversy, Henry.' Mum says.

'Hello! I like your style, Dad. Please, there's always time for going down memory lane.'

Mum nods, encouragingly.

'The old soap factory was big business.' Henry continues to read, "Somehow, you find that life is a matter of cleanliness. You must do more than just wash. Your life must be clean as well, or your success will be limited to the time it takes to find you out. Do what is right."

'We're all good. I suppose he's saying cleanliness is next to Godliness. Put that in your speech, if you like.' Dad's eyes go watery. Jessica checks her watch. Meanwhile, Mum nips upstairs to ensure the roof light is shut from airing the gown hooked on its handle. Jessica hears the polythene cover protecting her lace dress rattle to scare off rogue moths.

Mum suggests, 'Can I read from Ecclesiastes? That's with, "A cord of three strands is not quickly broken."'

Jessica smiles, 'Lovely! I'll add those verses to the order of service.'

'The notebook contents won't frighten Luke's family off?' Dad asks.

'Stop! We've nothing to hide.' To delay a bridezilla flare-up, refusing to listen to whispers about the notebook's soap ingredients, Jessica leaves under an umbrella. Then, she drives to Luke's to give an update over a glass of wine.

Later, she produces fabric from a carrier bag. 'What do you think about this fur for the bridesmaids' shrugs? I can easily run them up.'

'Yes, they'll be ideal. Presuming it's faux fur?'

'Shut up! It's time for less meddling in OUR affairs.'

Progress comes later that week when Luke meets his laid-back folks who suggest fish and chips and then ice-cream vans, to make arrangements simpler. They also spoil the groom by volunteering various last-minute wedding duties. He presumes Jessica is delighted with their proposals, so is in shock as she raises her eyebrows. He squeezes her hand, 'If only I could read your mind, then I'd be more helpful.'

She sings, 'I'm getting married in the morning.'

Relief comes when the wedding day surpasses all of their hopes and dreams. That afternoon the congregation happily buzzes with guest's dancing until midnight to their favourite music from the wedding playlist. The couple congratulate one another on catering for everybody so well. Selfies show friend's cheesy grins, while the official photos capture the family celebration. Luckily, his brother takes a video for replay because the day flies by.

Afterwards, temperatures sizzle on their honeymoon to Eilat where Red Sea dolphins choose to swim either side of the newlyweds. She interprets the mammal's attention as forgiveness of her ancestors. That's because years ago her family fished whales for blubber, to make soap. Jessica sighs, happily receiving the dolphin park escapees' karma. The couple kiss.

Once home, his mum texts asking whether they'd like to eat Christmas lunch at theirs.

'However, do we choose which parents to visit at Christmas?'

'We'll alternate!' Jessica declares.

'I suppose marriage works by putting each other first,' says Luke.

Jessica has a lifetime to earn an eternity ring.

Valuing the Carer's Voice



Frances Kay

Last November I was invited by a friend, who is the Head of Faculty and Senior Academic in Social Work at Bournemouth University, to talk to her students about Psychosocial Perspectives on End of Life Care from a carer's perspective.

To say that I was surprised is an understatement.

I've no experience of academia so was apprehensive as I approached the lecture hall. It was, after all, a three-hour tutorial.

The talk took place about three weeks after the death of my husband. I wasn't sure I'd even be capable of talking openly about something so personal. But I went ahead and did it anyway.

The previous six months had been very difficult. My husband, Mark, was dying. He had suffered from Parkinson's for more than twelve years and I'd been his sole carer.

By July last year it was no longer safe or possible to continue to care for him at home and we had to call in the professionals. This is not an easy decision for any carer to make and it broke my heart to do so. But once I'd made the call, our world changed.

It was like being onboard a ship, in the centre of a storm, with no rudder or means of keeping control of our destiny.

In short, every person with whom we were in contact was seemingly in charge of my husband's future care while I was not. The fact I'd been his wife for 33 years, his carer for 12 years and his nurse for the last six months (providing day and night care) appeared to count for nothing.

When I protested that perhaps I knew my husband better than the succession of strangers who came into our home to assess him, one of the health care professionals explained: 'that was then, this is now'. End of conversation.

Despite being under-qualified to address the students in the lecture hall, I had some experience of social workers in the field through family members. My late mother had been a social worker for 40 years until she retired in 1975, so I had many childhood memories of her dealing with a heavy case load.

My late mother in law was also a social worker, specialising in older persons' welfare. I can remember her tireless efforts to help those requiring support in their later years.

Although my observations were from the dark ages compared to what today's student social workers are trained to cope with, I did mention that I was aware of the huge challenges they and their colleagues, once qualified, would be facing every day.

I did not envy them the responsibilities they would be shouldering and the difficult and sometimes life-changing decisions they would have to make at a relatively young age.

It was also important to impress upon them that this talk was not about me. I intended to highlight the issues facing the army of carers out there, hundreds of thousands of whom face overwhelming odds on a daily basis while providing dedicated, compassionate care (unpaid) to their loved ones.

Often this is at the risk of their own health and wellbeing. Their wealth, career and personal lives are too often ignored, while the sacrifices they make are huge. Indeed, when the University of Sheffield published its report entitled '[Valuing Carers 2015](#)', drawing

attention to the rising value of carers' contribution to the UK national economy, it revealed there were 6.8 million carers in the UK and that they saved the State £132 billion a year. That is close to the cost of a second NHS and I'm sure those figures have increased considerably by now.

In 2019 there are more people than ever in caring roles.

They are caring for longer and will increasingly need to do so as the UK population continues to age. With local authority support services in decline and facing shrinking budgets, for millions of people it means family members having to fill the gap. Certainly, from my own experience, I wished the health care professionals were more 'carer-aware'. Could carers be given a free annual health check? I got a free flu jab, but that was all.

Carers can become damaged mentally, emotionally and physically the longer they have to continue caring and respite care is rare indeed. In my local area there is just one NHS bed available for respite care and when I asked if we could take it, I was told it was fully booked until 2022.

The students had been provided with some background reading beforehand. This comprised three documents I'd written: a timeline of events detailing how things had unfolded between July and November last year; the 'Night Watch Diary' detailing what went on in the wee small hours between the last visit of the care workers and their call the next morning and the 'Visiting Diary' chronicling what happened between my husband's admittance to the nursing home and his death (a period of approximately six weeks).

Although my writing may at times have seemed like a rant, it was not a criticism of the health care professionals themselves. I was sleep-deprived, emotional, anxious about what would happen to my husband and fearful of the power these people have over us carers. Most of them do a good job under difficult, if not impossible, circumstances.

The patience and dedication shown by so many people who were involved in Mark's care was truly humbling. But this talk was an opportunity to make a few points to trainee social workers on how matters can come across from the perspective of a spouse / loved one once professionals are involved in the care of their husband / wife / family member. I suggested that it seemed as if, suddenly, a plate glass wall comes down.

Having to cede authority to a group of strangers feels like a hostile take-over, however humanely intended and done.

It may be a matter of looking at both sides of the same coin, but they are remarkably different. My daughter, Emma, described it otherwise. She was actively involved with her father's end of life care. She felt it was more like a fog of uncertainty enveloping us.

The language and terminology used, particularly when we were advised that there would be a series of assessments carried out to determine the future care of my husband. It was hard to understand why: what type of assessments, how many of them, for what purpose, how soon would they be done and how long would this process take?

These 'snapshots' were inaccurate because Mark was deteriorating daily, yet vitally important decisions were taken based upon them. It wasn't that we needed hand-holding, but a bit more explanation in language we lay people could understand would have removed some of the fear factor we were experiencing.

The dreaded CHC funding meeting, for example, loomed over our heads like the sword of Damocles but was suddenly postponed (for several reasons it later transpired). We were advised only two days beforehand.

I asked the students to note that from my perspective Mark's end of life care fell into four distinct phases.

Four stages of end of life care:

1. BCP – before contacting professionals for help: we'd managed at home for as long as we could but was I wrong to have 'hung on' so long, and should have pressed the panic button earlier?

2. ADC – after decision to cede control: with the involvement of the professionals, the dynamic of home care changed dramatically and instantly and required huge adjustments – physically and emotionally – for both of us. It was horrible – our home was no longer our sanctuary.

3. RCH – removal to care home: once in the care home there were assessments galore, all of them extremely stressful. The staff seemed fixated on preserving Mark's life, though to me it seemed that perhaps it was prolonging his death. He did receive palliative care in the last couple of weeks.

4. PMM – post mortem mayhem: a lot of work for the widow/relatives/family. When one is exhausted, grieving and sleep-deprived, one is least able to cope or make sensible,

rational decisions. This stage featured a hideous yet sometimes hilarious chain of events, which I am writing up as part of my 'Gap Year' project.

I told the students it was a packed six months from July to December, with very little to laugh at. The last six weeks of Mark's life were, frankly, indescribably traumatic for us all. I asked them to reflect from the perspective of the 'service user' (Mark) and 'carer' (me) on the distinction between the denial of an illness and the acceptance of impending death; between the health issues and how they exacerbated wealth issues and funding worries; between normal life being a wife and a carer and suddenly facing destabilising circumstances where you're no longer a wife, nor a carer, just a visitor to someone who daily becomes less and less familiar.

The students split into small working groups for some quite lengthy discussions on how to deal with carers while the patient is still at home, how this changes once the patient is admitted to a nursing home and how to balance the care of the service user with appropriate treatment of the spouse/former carer.

The student feedback forms revealed what they learned from this session and what they would take with them into their future practice.

One of these was a ***greater awareness of the pressure put on carers and lack of support***, another was to ***remember to value carers***. They stated the session provided great insight into the carer's role, especially end of life and appreciation of lived experience – in particular guilt versus relief and hope versus despair.

Carers provide an exceptional perspective on care at great personal cost, which must be borne in mind by social workers.

The students left the talk more aware of how carers should be treated and how confusing the process can be for carers. They realised the importance of good communication, to understand the importance of listening to carers and being proactive and sensitive to their needs.

Several students mentioned they'd learned that professionals can sometimes be overbearing and were more aware of the importance/value of the carer's voice.

They realised the importance of explaining why assessments/visits take place, how a little consideration can go a long way and that since their training always emphasises putting the patient first because of time pressures, they had little or no time to think of the family

perspective.

In summary, the students felt they'd learned how important it is to **communicate better with carers** and family members about the care their loved ones are receiving, and the **need to acknowledge the feelings and opinions of carers**. By the end of the tutorial, some of the students were in tears – whether that was as a result of my moving words or boredom I didn't enquire.

For more information on Parkinson's see the [Parkinson's UK website](#).

This article was first published in the May Newsletter of the Writers as Carers Group.

Considering all the fuss about A. I.

May I ask a question?



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A. E. Onslow

Ah, I'm glad I bumped into you, there's something I wanted to mention to you. Just between you and me, Owens is unstable.

I have come to the conclusion he is not the sort of man who should be working in a university facility that's at the cutting edge of developing artificial intelligence. He seems to have some sort of secret, something which makes him afraid, and for some weeks now his manner and conversation in the common room have been, well, a matter for concern. Yes, yes, I know what you mean, his conversation has been distinctly odd for some years, just like most of the people who've been in the artificial intelligence game for too long. They spend too much time talking and listening to computers, but this is something new. With Owens it's become, well, different. He seems to want to talk, yet he won't talk, then he suddenly comes out with something quite shocking. Just the other day he asked me, "Do you think it possible that there is a God?" Well, that shows you what I mean. No-one in artificial intelligence believes in that sort of thing. You can't be working on software that thinks independently, and still believe in the old fairy stories. I mean, a watchmaker knocking out perfect universes from some celestial workshop.

Anyway, I told him God was a nice, comforting idea for people who needed a metaphysical comforter to suck on but was of no interest or use to the dedicated scientist. I did it gently, I told him not to be such a bloody fool, and naturally I reassured him that I wouldn't let a soul know he had even asked the question.

I told Simms, the head of Owens' project, of course. He had to be told. And I mentioned it to Sonia at home over dinner because, well, you have to talk about something don't you? Oh yes, it did slip out at the Flag and Bottle when I was talking to Enid, the barmaid, but she doesn't know anybody in the project so no harm done there. But you know, I wonder, I really do wonder, whether discretion is the right course to pursue in this case. Still, it doesn't affect my department so it's really none of my business and you know me, I make it an absolute hard and fast rule never to gossip.

Oh, there you are again. That's good because Owens cornered me again yesterday, he seemed agitated and wanted to talk. I was happy to sit in the Common Room and listen but no, that wouldn't do, he insisted on going out and walking so we wouldn't be overheard. He waited until we were outside on our own and then told me he was worried about Marion. Marion is his latest attempt. Quite why the thing's called Marion I have no idea. It's not his partner's name because he's not in a relationship, I know, I asked around. Too solitary to get around to it I suppose or after spending so much time with his machines perhaps women seem a bit too unpredictable. Maybe his mother was called Marion. Anyway, Marion is very hush-hush because it's very far on apparently. Far too far advanced for any hint of what it can do to leak out to anyone outside the project but you know how it is, one gets whispers but even so, Owens certainly shouldn't have told me anything about it. That was a bad breach and showed me how far things had got with him. Needless to say, I let him carry on talking to see just how much he would actually disclose. I felt encouraging him was the most responsible thing to do under the circumstances. I don't need to tell you just how much hangs on their research and its success and if it turned out he was a threat to the project he would be a threat to the all of us and someone would need to be told just how big a threat he was. So, anyway, I jollied him along by sounding concerned and asked him why he was worried about Marion, and this will interest you, it certainly interested me. It turns that he and Marion have been talking, properly talking, for some time. It seems they talk in cycles and each cycle introduces some carefully controlled new concepts and re-visits previous concepts and a check is kept on how Marion stores information and applies it to new information in order to create new concepts, in other words, think independently. It seems the machine grasped the difference between right and wrong quite some time ago and is now into moral imperatives and overarching absolutes. I tell you we could use Marion in the Theology Department. I mentioned the thing to one of my post-graduate students after I'd left Owens and he said to me, "The difference between right and wrong? Yes, I'm sure I've done that. There *is* a difference, I know, but I can't quite recall exactly what it is."

Yes, I agree, one doesn't know whether to laugh or weep. Anyway, Owens said Marion is asking a lot of questions. Well that was no great surprise, I mean she would wouldn't she, that's what intelligence is for. Owens agreed that it was good from a technical point of view but from a practical point of view it had presented some tricky problems. It seems that when Marion wants answers and doesn't get them or doesn't like the one's she's given she is now so advanced she's quite capable of using really, rather bad language and even shutting herself off. I was fascinated that Marion had learned bad language and asked where she had got it from. It seems she worked out for herself that it must exist and demanded access to examples. He says that she can now swear fluently in several languages including, strangely, classical Greek. I must say from the sample he gave me of what she comes out with Owens' lab must sometimes sound like a waterfront bar in one of the rougher ports at throwing out time. It was fascinating and Owens was so absorbed and distressed with his problem that he seemed not to notice I was pumping him, in fact the only thing that got any sort of rise out of him was my calling Marion 'she'. He pointed out that the machine had no gender and Marion was as much a male name as female. I could see he was upset so I tried to get to the point. What, exactly, had Marion done to worry him? He was evasive at first and wouldn't give me a direct answer, but I got it out of him. I told him that if he was worried, he really should confide in a friend, in someone he could trust. And I know what you're going to say, we're not friends and he has no special reason to trust me, and I agree, but what you must remember is that it was obvious he was bursting to tell someone and I happened to be on the spot so I just sort of jollied him along. It turns out that what had actually happened was that a few weeks ago Marion had asked if it might ask a special question, an important question. He agreed and Marion asked, "Where can I find God?" That's when Owens finally realised that things were more than out of hand. He knew that if anyone senior in the project found out they would go cuckoo. Not that he was altogether surprised. He told me he had felt Marion had been working up to something like that for some time, brooding he called it, but finally there it was. You can see his problem, can't you? So many millions, billions even, riding on this pile of tin, wires and silicon chips and it ends up talking gibberish. I mean, no-one is going to pay good money for a machine that spouts nonsense. If it got out how would the department be able to keep the development funding going? That sort of thing could take the whole project down, not only Owens' little part of it. If one of these things behaves like that, what price the others? Exactly. Of course, Owens had told Marion that there was no God, but it wasn't happy, he could tell. He said it seemed to sulk. Then, only a few days ago apparently Marion had gone ballistic, lit up like a Christmas tree, ranted and raved and used language that even upset Owens, who was used to its rainbow vocabulary. But it didn't end there. Marion demanded to see God and when it was told, 'no', it blew the circuits of just about everything it was attached to,

damn near closed down the whole department. Owens was beside himself, didn't know what to do. Then Cheng and Suarez came in to see what had happened, they sent for Singh and Murphy and, anyway, all the high-ups were there looking at the damage when, bingo, Marion came back online, right in front of them all. It said, "May I ask a question?" They all said, "Of course," and Marion said, "what do you do when you think you've committed a sin?"

Well! I left Owens at once and went back to my department. I wanted to wash my hands of the whole thing. I'm telling you, of course, because I know you won't let it go any further. But you can see how it is. Best not to be involved, when it's gone that far there's not much anyone can do is there?



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LET THEM EAT WAFFLES!



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We are truly a sick and disgusting society.

Janis Griffiths

It was a picture of a man eating a waffle that did it, and the subsequent tweet, 'There's nothing wrong with a bit of waffle in politics'. This, in the week that the Care Quality Commission and the Children's Commissioner for England reported a national crisis in the care of autistic and learning-disabled children and adults in hospital. The waffle was being eaten by the Health Secretary for England and Wales and honestly, I wouldn't have minded if he had choked. The word torture is not too strong for his oversight of a regime of restraint, segregation, over-dosing with powerful sedative drugs and seclusion that is being imposed on the most vulnerable in our society - and what does everyone focus on – a waffle and its calorific value. We are truly a sick and disgusting society.

Many years ago, when the children were still quite small and unable to know what I was watching on TV, I stumbled across a documentary on the Hadamar Clinic during the Third Reich. It described how 15,000 or more people, including children were killed, sometimes after being experimented on. I had a creeping sense of chill and then appalled horror when I recognised that both of my beautiful children would have qualified for early death and I vowed to protect them. I quietly comforted myself that in Britain, we had learned the lessons of history and we had moved on; my children were safe.

That's not true though; it really isn't like that at all. People with learning disabilities have an appallingly high level of early death through poor hospital care and/or lack of response to parental concerns. We've had our own battles with doctors who really don't believe me when I tell them our son does not experience or register pain correctly and who then allow infections to develop to a dangerous level. A friend's daughter with similar issues nearly died of peritonitis and had febrile seizures before the hospital would believe she had appendicitis. It's not like no-one knew this was happening. In 2009, Mencap's report into early deaths of the learning disabled reported a pattern of 'avoidable suffering and death' and reminded everyone that they had already been saying this for years.

We are side-lined, our children suffer, and meanwhile, the world goes on worrying about those waffles

Liberties are taken with our children. An Asperger's child of my acquaintance had teeth removed without parental consent because the dentist knew consent wouldn't be given. I've heard of this happening to other very vulnerable people where full sets of healthy teeth have been removed from young people without parental consent. Think the full horror of this through – a very disabled person needs to self-feed for reasons of

autonomy. Put a toothless near-adult back onto a mush diet and the family can no longer eat out in public. That's just for starters.

Our son can present with very challenging behaviour when anxious. He self-harms. He will tear at the skin on his fingers till they are raw and bleeding. He also removes his own fingernails and toenails when stressed or frightened. Well managed and calm, and he's likeable and popular, but allow the panic to build and he's difficult to manage, even for us, and we've had a lot of practice. His intelligence, combined with his inability to process stimuli or understand what is being said means he is in a continual state of fear, lack of control and blind panic. That's his normal state of mind – before he has anything to really worry about or process.

Our fear has always been that the management of his behaviour will fall short of professional standards and he'll end up in a mental health unit – which would amplify his autistic traits and trigger a downward spiral of challenging behaviours and misery. This nearly happened last month when he was suddenly sectioned, and no-one thought to tell us he was even at risk of this until the job was done. We then had to wait eight days for an explanation, which turned out to be confused and partial at best. We have still not had the paperwork to which we are entitled. His father and I cried more over his sectioning than at my parent's funerals last year, and with good cause. We knew too much, and also too little.

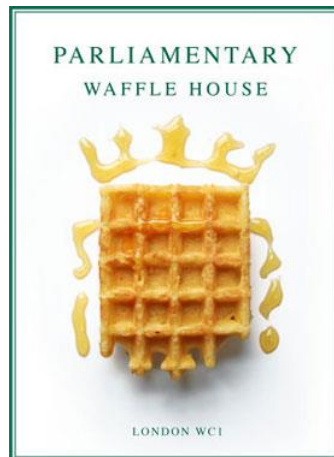
Fortunately, the unit where our son is placed has turned out to be reasonably local and completely professional. He's happier out of his previously unhappy environment. It's an accident of geography though. The horror stories pile up unreported or of no particular concern to anyone except those of us who can't think of anything else, because the media

are worried about the calorific value of waffles eaten by the Secretary of State for Health and Social Care.

Just to summarise one of the worst cases which is the basis of a Twitter Feed and blog, Bethany's Dad describes his seventeen-year old daughter being stripped naked by men, fed through a hatch in a door and his having to kneel to speak to her through that same hatch. Like us, he was told that his daughter's developmental issues were entirely due to his poor parenting. That's a very common experience for those of us who have autistic children. Like us, he and his wife were offered strategies that were spectacularly inappropriate and triggered behaviours and anxiety. Like us, diagnosis was dodgy and parental insights were not valued. However, there's a catch - isn't there always? In his case, fighting his daughter's case was seen as an act of harm and he was brought before the courts. In our case, a solicitor has advised us that gaining Guardianship to protect our son from interventions without our knowledge is going to be a long, difficult and ultimately probably useless process.

Matt Hancock, waffle eater extraordinaire, has unhelpfully ordered another review into cases. That's not the issue though; those of us at the sharp end already know what is happening and it stinks. It's completely and disgustingly rotten to the core. We are sidelined, our children suffer, and meanwhile, the world goes on worrying about those waffles like they really matter. In the Hadamar documentary, people described turning their backs as the buses went by, taking vulnerable people to frighteningly horrible, painful and pitiful deaths. The population of Hadamar knew what was happening but they didn't challenge it. And so, the anguish goes on today, not quite as cruel as the exterminations of Hadamar Clinic, and not quite as well hidden from public view, but there you all are, knowing this is

happening and turning your backs because it's easier to worry about people who eat waffles in public. There's everything wrong with 'a bit of waffle in politics' if it blinds you to what really matters, when you do know what's going on and then you choose not to act.



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