



But
Anne
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to carers everywhere

But

And now the moment we've all been waiting for - the overall winner of 'Carer of the Year Award'.

The glammy lassie fumbles wi the envelope, red talons in the way. She keeps wittering tae cover the pause.

Of course we know that every carer is a hero or heroine in their own right, but tonight the judges have had the impossible task of choosing just one to receive the award.

And there she is - Jill Harris from Milton Keynes, all poshed up tae collect her trophy and her cheque for two grand, which of course isnae really for her anyway - it'll go tae the charity she's set up for teenagers wi special needs.

Dazzled by the light, her sparkly blue frock contrastin wi the pallor of a skin that hasnae had enough sleep for the last nineteen, twenty, whatever years. The camera briefly glances intae the shadows where a figure in a wheelchair, presumably her child, huddles. Nae spotlights for him. Then the guy in the suit haunds over the cheque and the cut-glass trophy she does get tae keep, the glammy lassie kisses her and gies her a bunch a flowers and the poor wumman stands there, haunds full, tryin tae say thank you intae a mike that's set far too high for her.

*Would like to thank ..
so many wonderful ..
on behalf of ..*

She's tremblin; the guy in the suit hovers, ready tae swoop if she draps the trophy and it smashes in a million bits across the stage.

Jill, hen, I wish you could tell them the truth. Your truth, whatever it is; the lost years, the other weans you constantly felt guilty about neglectin, the stuff they don't want tae hear - just as they don't want tae see your wean, want him kept in the shadows. They want you tae stick your halo on for the night, even if it's made of plastic.

A stone has grown inside me. Been luggin it round for years and it's huge noo, has squeezed my heart intae a neglected corner of my chest. Back then, in the beginnin, it was a wee chuckie stane: snow white, veined wi grey dribblets, like marble. Marble is flawed but beautiful. Hard. So heavy.

My granny had a marble surface for makin pastry; its coolness kept the pastry light. My granny had cool haunds too, no like mines. At six year auld my haunds were always sweaty and no matter how hard I tried tae get them clean, no matter how often I washed them, there was aye some manky bit that got on the pastry, the leftover bit she let me roll out and cut intae wee shapes. When it was cooked my pastry was grey and deid lookin, no like my granny's, light and lovely. Afterwards she wiped the marble doon but gentle like, never scrubbed it. You have to be careful wi marble, it's porous. Not a lot of folk know that. They think because it's hard and tough it's waterproof but it's no. Water can seep in and ruin it.

Mibbe it's no a stone I'm carryin, mibbe it is marble, mibbe that's why it's that heavy - all the tears I've never shed, that have dripped inside me like an underground stream, they've made it that heavy. If it was stone, the water would shrug aff, drip for centuries and make nae difference. Like flint.

A lot of folk think that's what I'm like, hard as flint. Never want tae talk about it, never give up or gie in. A few year back they got us to dae counsellin. Yet another initiative. When they're no ignorin us altogether they have an initiative. A young lassie wi a psychology degree and big grey eyes.

How do you feel?

What d'you say? How can anyone understand? That's why we spend that much time thegether, parents of special children. That was another initiative, calling them special. Used tae be mentally handicapped. When they tellt me I couldnae bear to say the words. Still cannae. But in the

end what difference does it make what you call it. Special needs, differently abled, profound learning difficulties... how did I feel? How do you think, hen? Just hope it doesnae happen to you.

Only I can never say that - it'd sound as if I don't love my child.

Of course I love her. Of course I love her wi a passion almost unbearable, we're closer than breath, than heartbeat, but ...

You can love someone with the all the fierceness that's in you and still wish that things were different.

But.

Everyone hopes their baby's perfect; they smile when they're supposed tae, laugh and run around, are toilet trained at three and at five you wave them aff tae school and have a wee greet cause you're lossin your baby.

I'll never lose my baby.

She's taller than me noo, and heavier, but she's still my baby. Just as she was the day they finally broke the news and tellt me tae go home and love her.

Love is all you need.

I needed a new washing machine. Extra sheets, clean claes three times a day; I couldnae bear if she wasnae perfect, if there was food in her hair or dribbles on her sleeve, hated anyone tae feel sorry for her, no respect her.

Now I could do wi a new back. All carers have sore backs. Must be from carryin their stones. No the weans, no them. Stones made up fae guilt, fear, anger, and always, always, bein far too responsible.

There were two Paulas.

The first lasted till she was eighteen month auld. A pretty wee baby. She smiled at six week, slept through the night at six month and at one she hauled hersel up and stoated round the house haudin on tae the furniture. Giggled and crowed in her buggy, planted wooden bricks on top of one another, smiled wi her pearly teeth.

Then she stopped. Stopped finger painting, stopped turnin the pages of her toddler books, stopped being the baby we knew.

The first time she had a fit I thought she was dying, jerkin as if she'd been electrocuted. Afterwards her haunds fluttered like lonely wee birds.

Blood tests, hearing tests, eye tests, psychomotor skills and God knows what else. Left in a room alone wi her for three days, no knowin what was happenin, while folk wi folders came and went.

And at the end, what? Profoundly mentally handicapped. Take her home.

How can your baby die but no die? Become another child, another Paula.

She's still there in her eyes, her eyes tell me what she's feeling and what she wants. She is joined to me so closely that I often dress us in the same colours, no deliberately as I never have time tae think about what I'm wearin, just how it happens. Her pain is my pain, her joy mine. There's been lots of joy, far more than you'd imagine. And the folk we've met - other parents - wonderful, amazin folk you'd never of known otherwise. Like Helen. Don't know what I'd do without Helen. Laughed till we thought we'd die at times, but ...

But I'm tired, dead tired. The experts said she'd be gone long ago. But the experts were wrong. I'm scared for the future. No one else can read her eyes.

Flick through the channels ... a pop quiz, a hospital soap, an eighties film ... I try but am drawn magnetically back to the Caring Awards. This presenter lassie in her lowcut frock and expensively streaked hair must of drawn the short straw. Mibbe she hopes she'll get noticed by some TV executive mad enough tae be watchin this instead of young Tom Cruise. It'll be dead cheap tae make, but, just a few speeches and a free dinner. Feelgood factor for the sponsors. They show a short video of what they describe as the reality of life for carers. Ha ha. A sunny spring day in the park. Nice-lookin young couple push a two year old with Downs in her buggy. She's laughin. Pink outfit. Very cute.

We are the forgotten ones,
We are the ones whose eyes you don't want to meet.
We do unspeakable things in public toilets, clean smelly messes, wipe snotty noses, humph round bags of giant nappies.
To you, our children are not cute; you turn away from them as though they were invisible. That's what hurts most - you don't see them the way we do, miss their beauty, shot through with pure gold. We are strong, having spent years of our lives lifting and laying, holding and helping, existing on less sleep that we would ever have thought possible. Like vampires, we don't look much in mirrors. And if we did, no doubt we'd find that we, too, are invisible.

The film moves on tae a centre. For wee wans, of course, no adults, that might be too real. Pastel walls, shelves heavin wi building blocks and paints, one helper for every wean. Of course they don't tell you that the parents probably had tae fight for years wi the council, run jumble sales, sell raffle tickets, write endless letters tae get it. But, hey, just polish your halo and get on wi it.

Back to the glammy lassie on autocue. *One of the most heartening things in recent years is the way that some conditions have become better understood.*

She smiles beatifically at the audience.

Like autism.

Oh God they're gonnae trot out the Rainman routine, updated for the 21st century, as if they were all wonderfully talented and actually with a bit of careful handling everythin could be just hunkydory - footage of autistic savants doin tricks, drawing cathedrals or recitin train timetables backwards.

I wonder if Helen's watchin this. Her Sam's 28 noo and, unlike my child, he's far from invisible. It's what goes on inside him that's invisible.

Helen's the calmest person I know, doesnae rant like me. If there's a boiling volcano underneath she never lets on. But with every year that goes by, things seem tae get harder.

At yesterday's advocacy group, they tellt Sam it was up to him if he took his medication. Respect for the individual, they said.

Sam has the choice to say no.

And if he says no, what's Helen's choice?

If he says no and is bouncing aff the walls,

or beats up his brother what choice does she have?

He can't make choices.

Overprotective mother. That's what they always think.

Everyone can be helped to make choices, even limited ones.

Sam doesnae understand the concept of choice. If you gave him a choice he wouldnae eat. He doesnae like eating, has nae sense of taste and a heightened sense of smell which puts him off most foods.

*He's a highly intelligent young man - he has an IQ of ..
I'm his mother.*

I know it's hard.

You know nothing.

He paces round the table while everyone else eats shepherd's pie. He doesnae like food mixed up - it has to be separated out. And he'll only eat food that's symmetrically shaped and tastes totally bland. At his place there's a perfectly round beefburger, home-made from organic mince wi nae seasoning. Helen coaxes him to eat a few mouthfuls.

He's painfully thin - you can see his ribs show under the red tee shirt. He's got seven of them, each printed wi the day of the week. God help Helen if she gets behind with the washing and doesnae have the right day. The social worker suggested she get two sets of tee shirts but he can smell the difference.

When he was wee he used tae smell her hair. She loved that. Sometimes even noo when he's quiet and calm, he'll dae that, sit beside her and smell her hair. I've watched them. She shuts her eyes and enjoys his closeness, kids hersel on for that brief moment everythin's okay. But if he stops takin his medication these quiet moments will go. He'll be hyper, birling round the room, listenin tae music till three in the mornin, too exhausted to go tae college the next day, he'll get out of his routine and his routine is the only thing that keeps them all goin.

It must be his choice.

He can't make choices.

How come these folk think they know better than us - the mothers, the fathers, the ones who look after our children every day of their lives. Even when they go intae respite there's nae respite for us, sleeping in slivers of the night, always wired up for the phone tae ring.

They're gonnae finish the show wi a word from their sponsor - the mobile phone company want us all tae be in touch. Then a final glimpse of the tired lady in the blue shiny frock, clutchin her trophy and her dreams.

Switch the kettle on. Cup of tea afore bed. He's on night shift the night and I never sleep as well without him. Sit for a while starin at the gas fire, watch the fake flames flicker over the fake coal.

We had a real fire when I was wee - used tae spend ages watchin it. I thought there was another world in the

fire, wi jaggy mountains and red sunsets. The coal was all different shapes and sizes: wee bits tae start the fire, muckle great lumps tae keep it gaun and dross tae damp it doon at night. But there's nae magic in this fire so I switch it off and watch it fizzle tae nothing. I know I should get tae bed then at least I'd have a few hours afore she wakens and the moanin starts, but I feel as if I'm glued tae my seat.

Eventually I rise, push Paula's door open a crack and steal in, stand beside her bed. Her mouth is open and she breathes loudly but her eyes are tight shut and a wee hauf smile licks round her mouth. Her soft, soft hair is spread out on the pillow. I raise my haund to stroke it, touch it ever so gently in case I wake her. She moans a little and makes a slight movement, then relaxes again intae deeper sleep, her breathing quieter like a baby's.

My precious one. My baby.

Anne Donovan is the author of the novel *Buddha Da* and the short story collection, *Hieroglyphics*, both published by Canongate. *Buddha Da* was short-listed for the Orange Prize, the Whitbread First Novel Award and the Scottish Book of the Year Award. It won The Prince Maurice Award in Mauritius.

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