

REGRETS OF THE DYING: HEATHER

EP 1

SILENCE.

**NARRATOR:**                   **17 years ago, Heather Pratten's life changed forever. She's 80 now, but I have to confess I was pretty nervous meeting her. I'd read about her story, and wasn't sure if she'd be okay talking about had what happened again.**

**I needn't have worried.**

**We met in her spotlessly clean home in semi-rural Essex. She made me a cuppa, we sat down; and she told me how she helped her son commit suicide.**

MUSIC.

**NARRATOR:**                   **I'm Georgina Scull, and you're listening to Regrets of the Dying.**

I was convinced he was going to be a girl. But he wasn't, he turned out to be a boy and I never had a name really ready for a boy and I can't believe that I named him Nigel. He hated the name and he always called himself Nige, so we all called him Nige.

Nigel was very independent and he loved to draw. You would always get hand drawn cards for Christmas and your birthday. His flat was always full of friends. It was open door, really. He just loved being around people, but if any girlfriend tried to get too close, he wouldn't have it, because he said to me, nobody is going to look after me. I'm not going to let anybody look after me. I don't want to be looked after. So that was how he led his life. Then suddenly he was phoning me a little bit more and then he said, oh, I'm taking redundancy from work and I said, oh, it's too soon for that. He said, oh well, things are happening. So I said, what? He said, oh nothing, I'm okay.

So, we just sort of rolled along. We just got on with life.

**NARRATOR:**

**Nigel had Huntingdon's, a genetic degenerative disease of the brain; a mixture of motor neurone, muscular sclerosis, and Parkinson's with symptoms usually developing between the ages of 30 and 50.**

**It damages certain nerve cells in the brain, and this brain damage gets progressively worse over time, effecting movement, perception, thinking, judgement, and behaviour. There is no cure for Huntingdon's.**

I was seeing Nigel regularly. I used to go out for days with Nigel and we would laugh a lot because he was really funny, he had a good sense of humour, but we always came back to ways to die, even though he always said he was fine. But then one day I got a shop-bought card, and I knew that he couldn't draw any longer.

It really hurt him that he couldn't draw. He wasn't what I call a great – I don't know, what's the right word for it? He drew cartoons. He made you laugh with his cartoons, and he would draw comics, and his friends, you could recognise his friend's been the character. He drew them as pirates and things like that and he would send you funny cards. When he could no longer draw, he was cutting pictures out of magazines and sticking them up on the wall to make a collage and when he could no longer use scissors, he used to get bits of material, patterned material, and arrange that, because he just had to do something that was artistic. He just liked to create something.

Then things got – Nigel was talking about finding ways to die.

He did say to me, oh, I've been round the train station twice, but I can only think of the driver and I don't want a violent death.

He'd tried the train station; he wouldn't do that. He tried starving himself; he got over that. But then he was always talking about it.

He was beginning to lose walking, he was having difficulty swallowing, he couldn't put – at that point in time there were videos, he couldn't get his videos in and out to watch. Everything was sort of going.

He could no longer use a knife and fork either, and when we went out, we would eat with our fingers, we would have lunch and we did get funny remarks from people about the fact that we both ate with our fingers, because I did it the same as him. We would go to Lakeside for the day, perhaps watch the cinema, feed the ducks, look round the shops, have something to eat and we had nice days. But it always came down to how would he die. By this time he'd gone back into hospital again, because he was having real difficulties, and like a lot of Huntington's people, they get very hot, their temperature rages out of control and he hated wearing clothes so that to have carers come in with a grown man who didn't want to wear clothes, that was not proper. So he just wasn't looking after himself, and he would leave clothes piled up by his gas fire, and I was really frightened there would be a fire. So eventually, he went back into hospital and we went out once a day every week. It was really good, because we became really close and he would talk to me about a lot of things in his life, but it always came back to how he would die.

But always there was this compulsion that he wanted to die.

Then he said to me, I'm going to stay with my friend for a little while, so don't come and see me. But I kept phoning and one day he picked up the phone and he just said, help me. When we got there, he'd been trying to starve himself and he was so thin, it was unbelievable. He'd been using vodka to keep himself unconscious and he'd run out and he was too weak to go to the shop himself. When he said "Help me", he really meant, "Go and get me some more vodka". Instead of that, I

called an ambulance and he was taken into hospital. He was furious, and he said to me, "If you ever do anything like that again, I'll never speak to you again." But they got him to start eating and he did go home again.

Then it was his birthday and I was going to take him out for the day.

I collected him from the hospital and we were going to go down to Southend for the day and he said, no, no, I want to go back to my flat. He said, I like my flat. So, okay, so we went back to his flat and I was saying to him, well, what shall we get to eat then for lunch? And he said no, no, no, it'll be all right, don't worry about that. So we got back to his flat and I got out his cards and his presents and he said, no, no, no, don't worry about that, it's too late. I said, no, I'm going to get your cards out and I'm going to sing happy birthday to you. So we did that and then he said, my friends have got me what I wanted. He came back from the bedroom with a syringe and a packet of pink stuff, which I presumed was heroin. He said, they've told me what to do. I put it on a spoon with water and heat it up, and put it in the syringe. So he did that, but his movements were so bad, really, that he didn't get a lot in the syringe and he couldn't inject himself. He was just trying and it was falling on the floor and I was picking it up and giving it to him and then he looked at me and he went, oh, I can't be bothered with all this, he said. He just grabbed all the powder up and he just swallowed it. Then he looked at me and he went, oh, that was vile. So, he had a drink and then I said to him – he sat in a chair, but his movements were a bit rocky.

So, I said, look, let's lay down.

So, we lay down together we talked about his life and we just both went to sleep. Then it was about three or four hours later when I woke up and I looked at him, and I'd been a first aider and I knew he'd nearly gone. His face was really deathly white. His lips were bright blue and

he only took a breath now and again. I just couldn't stand it any longer. I just thought, this has got to end. So I just picked up the pillow and I put it over his face. It wasn't for long. It was only a very short time. And when I took it off, he didn't breathe again,

and I sat there with him, I sat there with him for about half an hour and then I called the police.

I had no idea that his friends had got that for him. I thought we were going out for his birthday, but it didn't take long to adjust to the thought of it, because he wanted it so desperately and he was really happy about it. He said to me, this really is a happy birthday and he said to me, if you call anybody, I'll never speak to you again. I said to him, if this works, you'll never speak to me again anyway.

We hugged each other and we both laughed because it just seemed so right. It was right for him.

Well, when the police arrived, I just said he'd taken an overdose of heroin and they took me to the police station and interviewed me. I never told them I put the pillow over the face at that point.

I had to go back after the weekend, and I couldn't keep it inside, what I had done, because it was such a big thing. So I told them everything, that I'd put the pillow over his face, I told them everything. So first of all I was on a charge of murder and then that was dropped to aiding and abetting a suicide, which I was quite happy to plead guilty to because that was what I did. I helped aid and abet suicide. I helped Nigel to achieve what he wanted and I have to say that the law was very good to me.

The police treated me very well, and it was fortunate for me that his post mortem autopsy revealed that what I did with the pillow didn't make any difference, because he was practically dead anyway, which for me was a really big thing, and it also saved me from prison.

I can't explain to my state of mind at the time. I'd had a few years of him keep saying he wanted to die and trying to find a way and we were discussing it. I knew it would come to it, but I just wanted to be there with him, not to actually do it, but at the end of that time when it all happened, I just felt he can't fail, it's got to happen and just to see him lying there, I just thought, it's got to end.

**NARRATION: Heather was tried for aiding and abetting Nigel's suicide at the Old Bailey. The judge conditionally discharged her for one year, citing "exceptional circumstances".**

I had five children. The eldest son, he's actually had the test now and he hasn't got the gene, and then I had Nigel and Philip and then the two girls.

Philip and Nigel both had the disease.

Nigel was 42 when he died, Philip was 50. He went the full length of the disease. At the end, Philip actually starved to death, because he could no longer swallow and didn't want to be PEG fed and it took him I suppose about 10 days, six, seven days to die.

It gets a bit muddled up with Nigel and Philip, but then I always think everyone ignores Philip so I always say a little about Philip because he had it as well. But he would never have said that he wanted to die.

We never told Philip about Nigel. We didn't want to upset him, and they were never very close when they were children anyway. What was really strange is on the day of Nigel's funeral, Philip suddenly walked up and punched a glass hole in internal doors, the glass, he suddenly punched through the glass. He didn't know why he'd done it, he couldn't give a reason why he'd done it and the nurses didn't know

why he did it. We just felt that was really weird that he'd done it on the day; he'd never done anything like it before or after, just felt that was a bit weird, actually. As if he was marking the day. So no, we never told him, we didn't think it was in his – well, we didn't think it would do any good anyway.

Nigel always said from the beginning, if I ever got it, I'll just shoot myself because they saw their father and they knew what it would entail.

But Philip seems entirely different. You could wait on Philip hand and foot and he loved it, whereas Nigel wouldn't let you do anything for him. When it got to the stage where he had to be shaved and he just hated it, that the nurses were shaving him and couldn't do it himself. That wasn't what he wanted.

Their father died earlier of a heart attack, not knowing what it was, he had a lot of wrong treatment. He had electrical shocks given to him and other wrong treatment which he should never have had, and he died early of a heart attack. So, he died when he was around 40.

He was seven years older than me. One of my friends from school used to belong to the Methodist youth club and I started going there with her and I met him there and we just got on really well. He was living with his brother because his mother had remarried and moved down to Portsmouth and he was living with his brother. I'd never really got on with my mum, and he'd obviously had a very troubled childhood with his mum, because she wasn't an easy person, and he'd seen his father try to commit suicide a few times. I wasn't – I loved my dad but I wasn't all that happy at home. So we sort of bonded in a way and decided we'd like to get married and have our own family, which we did. Kenneth. Ken. Yes, so we had our children.



We didn't know that he had this disease. His mother hid it. She said her husband had died because he had a nervous breakdown because of the War. So he was in – they called it mental hospitals then, psychiatric hospitals now. That's what it was. But years later, when someone was doing our family tree for us, I was contacted by a chap in Canada, and he said, well, she did know about it, because her husband was my mother's brother and we knew my mother had it, and we wrote and told her, and it was only two years before she died. She just said, never contact me again, never contact my children, you're lying. But when – my solicitor got papers going back from that time and the doctor had written on it: Huntington's disease; family not to be told. I thought that was the doctor's decision, but later on I realised obviously it was her decision that she didn't want them told.

There isn't actually a safety zone, because people get it at all ages, but as far back as we could go, it's always hit in the early 30s. In fact going back through the years, in direct descent to their father, family members were dying around 70. Then all of a sudden a woman named Martha Brown married into the family and after that the direct descendants, they died at 50. So, we presume that she fetched the disease into the family. As far back as I can trace, everyone in our family had it from 30 to about 50, they would die around about 50 and as my girls, my eldest sons are well over, they're in their 50s and 60s, so we presume that they're free. Well, I know that they're free from it.

**NARRATOR:                    I wondered, if Heather and her first husband had known he had Huntingdon's, would they have done anything differently?**

We probably wouldn't have had children, but then – how can I say that I would want to be without them? My children have had to grow up knowing what could be in front of them, making the decision that they shouldn't really have children to pass it on, because it is a dreadful disease. It takes 25 years to kill you, so it's a long, long process, and

they had to grow up knowing that that could be theirs. So I said to them, look, you've just got to make the best of the life you've got, you've got to do what you want to do providing you're not hurting anybody else, obviously. But you've got to live your life as you want it, not have any regrets.

I can't regret that I had the children. I do regret that it's messed up their lives, that it's taken away options they should have had. I do regret that it wasn't a normal, absolutely normal family life that they grew up in, but we all did the best we could.

I don't have any regrets about what I did, because it was his wish. He did not want to endure the last years of that disease just laying in bed looking at the ceiling, unable to walk or talk, eat properly, that was never Nigel. He would never have done that. And I'm pleased he never went under a train or had a violent death. So the only thing I regret really is that he never had the chance to have a full life. I think what he did was right for himself, and I think I was right to stay with him and help him because he didn't want to die alone.

It's so difficult to find an easy way to die if you haven't got proper medical help. Nigel would have loved everyone to be with him; he would have liked to have said goodbye to everybody, but that wasn't possible.

**NARRATOR:**                    **As with so many of the interviews in this series, the things Heather regretted weren't the most obvious; it wasn't how she felt compelled to help her son. It was another, related, choice she had to make years before...**

I couldn't manage five children and my husband. He had it quite bad mentally actually, and he went into a psychiatric hospital, but his one wish was to come home, and I just couldn't accommodate him at home.

So, you get feelings of guilt afterwards that you never looked after him properly, but at that time it just wasn't feasible.

He was really upset at not been able to live at home. That is a deep regret of mine, actually, but I know that I couldn't have managed him and I couldn't have managed the children. That wouldn't have worked anyway. But you still regret it. You still feel guilty about it.

He used to get very upset at not being allowed to come – he used to come home and visit, but then when it was time for him to go, a lot of the times I had to call the police and he didn't like that. But he wasn't the sort of person that – he was a lovely man, he wasn't the sort of person who would hold it with you but obviously, Huntington's disease changed him and he could be quite belligerent and slightly aggressive. But that wasn't his normal behaviour. There was one day when the hospital tried to stop him from coming, they took away his shoes and his clothes, and he walked from Goodmayes Hospital all the way nearly to Romeo Corner in Romford with no shoes on his feet, just a dressing gown and it was snowy weather, before anybody got him stopped by the police.

But his one desire was to be at home and I was thwarting that, really, which – but I know that I couldn't have managed him. Hard to do actually because it is difficult, but I can't change what happened.

No, I just had to let it go.

**NARRATOR:** Heather Pratten is now a patron at Dignity in Dying, a not-for-profit organisation that campaigns for an assisted dying law in the UK, allowing terminally ill people some choice about how and when they die.

She wants to help others avoid having to face the same agonising decisions she's been forced to face.

As I left, Heather gave me a little bag of toys. She remembered that it was my daughter's 7<sup>th</sup> birthday that weekend.

Personally, I think the world could do with a few more Heathers in it.

SILENCE.

MUSIC.

**NARRATOR:** You've been listening to, Regrets of the Dying.  
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