

# I AM BREATHING



*Press Coverage*

★★★★★ The Times  
★★★★★ The Sunday Times  
★★★★★ Mail on Sunday  
★★★★ The Guardian  
★★★★★ The Herald  
★★★★★ Empire  
★★★★★ Financial Times  
★★★★★ The Daily Express  
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★★★★★ The Metro  
★★★★★ About  
★★★★★ Independent Radar Magazine

RTE ★★★★★  
The Sun ★★★★★  
Female First ★★★★★  
Fancarpet ★★★★★  
Celluloid Heroes ★★★★★  
The Skinny ★★★★★  
Mail on Sunday ★★★★★  
Britflicks ★★★★★  
Screen Invasion ★★★★★  
Radio Times ★★★★★  
The FT weekend ★★★★★  
The Upcoming ★★★★★



## WELCOME

Following on from the amazing success of our Global Screening Day on June 21st there has been a big demand from people across the UK to see the film in their local cinemas. An online petition generated over 1000 signatures in just 30 hours and your cinema was one of those suggested to us!

To give you an idea of the publicity our film has enjoyed we created this press pack for you. It contains all press coverage on television, radio, in newspapers, and various magazine publications.

If you are interested in booking this film please contact Rebecca Day:

Scottish Documentary Institute | SDI Productions Ltd

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T: +44 131 651 5872

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In our experience the screenings are best supported by a health care professional or local MNDA member. If you would like us to connect you with anyone from your area please let us know.

## ABOUT THE FILM

I AM BREATHING is a documentary about the thin space between life and death. Neil Platt ponders the last months of his life. Within a year, he goes from being a healthy young father to becoming completely paralysed from the neck down. As his body gets weaker, his perspective on life changes.

*"It's amazing how adaptable we are when we have to be. It's what separates us and defines us as human beings."*

Knowing he only has a few months left to live, and while he still has the ability to speak, Neil puts together a letter and memory box for his baby son Oscar. How can he make sense of the last 34 years? How can he anticipate what Oscar might want to know about his father in a future Neil can only imagine? He tries to tell the story of his life from his memories and impressions of love, friends and motorbike rides.

Neil faces motor neurone disease with incredible humour and honesty, determined to share this last stage of his life through a blog, which touched many people. With his posts forming the film's narration, I AM BREATHING tries to listen to Neil as he asks "what makes us human" in the last months of his life.

## RADIO AND TELEVISION APPEARANCES

### ITV: THIS MORNING

**Monday 17<sup>th</sup> June 2013**

Interview with Louise Oswald

<http://www.itv.com/thismorning/life/living-with-motor-neurone-disease/>





**ITV LEEDS**

**18<sup>th</sup> June 2013**

Interview with Matt Platt

<http://www.itv.com/news/calendar/update/2013-06-18/filming-the-fight-with-motor-neurone-disease/>

**BBC BREAKFAST**

**Saturday 22<sup>nd</sup> June 2013**

Interview with Louise Oswald



**BBC WORLD SERVICE - Outlook**

**Wednesday 19<sup>th</sup> June 2013**

Interview with Louise Oswald and Emma Davie



**BBC RADIO 5 LIVE**

**Stephen Nolan Programme**

**Friday 21<sup>st</sup> June 2013**

Interview with Louise Oswald



**BBC RADIO LEEDS**

**Monday 17<sup>th</sup> June 2013**



**BBC YORKSHIRE TV NEWS**  
**Friday 21<sup>st</sup> June 2013**  
Interview with Louise Oswald



**STV**  
**Monday 17<sup>th</sup> June 2013**  
<http://local.stv.tv/edinburgh/133051-young-fife-widow-aims-to-raise-awareness-of-the-disease-which-killed-her-husband/>



## THE TELEGRAPH MAGAZINE

Saturday 1<sup>st</sup> June 2013

Interview with Louise Oswald, Emma Davie & Morag McKinnon

<http://www.telegraph.co.uk/culture/film/film-news/10084600/I-Am-Breathing-film-follows-dying-fathers-last-months.html>

One evening in late October 2007 Neil Platt returned home after a busy day at work. Platt, 33, an architect, walked through the door of his London house and immediately sat down. Without taking off his coat, he removed his shoes and socks to inspect his toes. There was something not quite right with his right foot. Neil told his wife, Louise, that he had been limping during the day but that, oddly, he was not in pain. The foot seemed to be 'slipping itself' on the ground. Louise reassured him that it was probably nothing, suggesting he might just need new shoes. But there was something else. Neil now noticed that he could not lift the foot on his right foot as high as he could those on his left. He made an appointment to see his doctor. Louise was not mildly worried until Neil returned from the appointment: the doctor had given Neil his personal mobile number, insisted he undergo several tests and, because of Neil's family history, referred him to a neurologist.

Neil had his suspicions about what was wrong. Louise was less concerned. But when Neil's mother came to visit a few weeks later and saw her son limping towards her at King's Cross station, she knew immediately what the matter was. The last time she had seen that limp was on her late husband.

Neil's father, David, had died at the age of 50 from motor neurone disease (MND), which had also killed Neil's grandfather at 62. His father's death had made Neil acutely alert to the first symptoms of the disease. When he was 22 had been to see a genetics specialist in an attempt to assess his chances of developing it. After six months of research the specialist came up blank. He could only say there was a 50-50 chance that Neil was a carrier of the same defective gene as his father and grandfather, and even that was a guess. But on February 7, 2008, after doctors had eliminated every other option (there is no specific test for MND), Neil was diagnosed with the disease.

MND is a brutal, merciless disease that rapidly causes physical deterioration, leaving sufferers unable to walk, swallow and eventually even breathe on their own. Someone with MND can typically expect to live about two years from diagnosis. It affects 1,000 people in the UK, with about 1,000 people diagnosed each year. More men than women are sufferers, and it is predominantly a disease of middle and later years (Neil was at the younger end of the spectrum). Although there is a genetic factor for some of those affected, the science is unclear on the causes. But while more than 1300 million is spent annually on cancer research in the UK, the average annual spending on MND research is £2 million.

There is no treatment for MND, just management. So far only one drug, riluzole, has been developed for people with the disease. Riluzole can slow the rate of deterioration and extend life by, at best, about six months. One often hears stories of people battling and beating cancer, but no one beats motor neurone disease, once Neil was diagnosed, everyone knew how the story would play out.

For Neil and Louise the diagnosis seemed particularly cruel because they had recently become parents. The couple had met in 1994 as students at Edinburgh's College of Art, but they had only

begun a relationship a decade later when they ran into each other at a mutual friend's party in London. They had been dating for a few months when Neil surprised Louise on holiday in Portugal by asking her to marry him. 'We hadn't been together for very long, but that was Neil – so cheeky and confident', Louise said as we sat together in a cafe in Edinburgh. 'The harmun looked relieved when we got back to the hotel and Neil gave him a thumbs-up.'

They married in November 2004 in a Scottish stately home. In the wedding video Neil can be seen, in a bow tie, kill and solemnly, dancing with Louise in the evening cocktail. They moved to south London, and Louise became pregnant. Their son, Oscar, was born in August 2007. By the time of Oscar's first Christmas, Neil and his doctors were fairly sure that he had MND. 'My most vivid memory of that time is of when we went to my parents' in Edinburgh', Louise told me. 'I went for a walk at the beach with my mum and Oscar and it was the first time I told my Mum about there being a real possibility that Neil could die. I remember holding in the tears until I said, "How am I going to tell Oscar?"'

As the disease took hold, Louise found herself having to look after two dependent males. By Christmas 2007 Neil was supporting himself with a stick by the time April he was in a wheelchair. There were times when the disease progressed with alarming speed. There was a big jump in 2008, between Neil's birthday in July and Oscar's birthday in August, Louise said. 'On Neil's birthday I have photos of him wearing fingerless gloves, meaning he could push his

**One hears of people battling and beating cancer, but no one beats MND; once Neil was diagnosed, everyone knew how the story would play out**

own wheelchair, and by Oscar's birthday he couldn't lift his arms, needed a head rest and had lost a lot of weight. He was gipping like a fish. By September 2008 Neil could no longer use his arms at all, and Louise had to feed him. 'The physical parallel between Oscar and Neil were unbelievable', Louise recalled. 'I started having to spoon-feed Neil just as the spoon was being grabbed off me by Oscar. Oscar was pulling himself up just as Neil had to start using a hoist to pull himself up. And when the wheelchair arrived, so did the baby walker.'

'I must have been hard to reconcile myself to this turn of events', I suggested. 'The fact I had a baby did me a huge favour, Louise, who had worked in film and television containing before having Oscar, said, "Because you go from being someone who is selfish in life to being a mother, to being a carer, and I was just doing all of that at the same time." Did you ever give in to selfishity or envy at those not in your position, I wondered. Louise replied by telling me a story. The family had gone on holiday to Morocco with some of Neil's relatives. Oscar was ill with a tummy bug. One morning he woke early and Louise pulled him

## Every breath I take

When, soon after the birth of his first child, Neil Platt was diagnosed with motor neurone disease, he knew he would never see his son grow up. His determination to make the most of their short time together, and to draw attention to the horrors of MND, are captured in a moving documentary.

By Sarfraz Manzoor, illustration by Keith Negley

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into bed, when he had his diarrhoea. I remember putting Oscar into the bath to wash him', she recalled, 'and I turned and Neil was standing in the doorway on crutches. That suddenly he came and sat on the floor. That low point prompted Louise to change her outlook. I started not thinking from selfishly to thinking how privileged I was to be going through this with Neil and how he was on this part of his journey through life', she said.

Neil's condition meant that Louise needed at least two other adults in the house at all times, then if possible, three. To fill the calendar with whoever I could get – friends, family, they all worked as a tag team and gave up their time', Louise said. 'We also had two palliative care team members every week meeting who came to wash and dress him'. And then there were the other specialists who were in and out of the house: the GP, district nurse, palliative consultant, social worker, occupational therapist, speech therapist, dietitian, physiotherapist, MND nurse specialist, respiratory specialist, bloods nurse and night nurses.

The family moved to Hargrave so they could be close to Neil's family and Neil transferred to the Lamb branch of his architecture firm. To get to the office he would take a taxi to the station and then use a walking frame, but once he began to lose mobility in his hands, seven months after his diagnosis, he had to give up work. His brother Matthew, who is younger by five years and works for the police, took six months off to help. 'I did all

diagnosis', he wrote. 'Having been here before with Dad, it was never going to be pleasant. Stage two was to ignore it for as long as possible in order to enjoy every possible second with my beautiful wife, and newborn son in our newly bought family home. Stage three arrived when it was no longer possible or realistic to ignore the symptoms.'

In summer 2008 Morag McKinnon, a drama director who had made a number of short films and who had known Neil in Edinburgh, came across the Mc-Kinnon family, suggesting they make a film about Neil. Neil immediately agreed to let the documentary makers spend several months filming him. 'For me the film was so ethically complex that at first I didn't want to make it', Dave said. 'But when I met Neil the force of his desire

international screenings to come on June 21 – MND Global Awareness Day. 85 per cent of their profits will be donated to the MND Association, the other half donated to outreach work. The film is bleak, unflinching and moving, yet mortally funny. In one scene Neil describes trying to arrange for his phone to be disconnected. 'They want to know why I want to end my contact', he tells the camera. 'They say, "We have some great deals", and I say, "But I'm doing so, I don't need to use the phone," and they say, "Would it make a difference if we threw it three months away?" I said then, "If you can do that, you're better than all my doctors put together."

'They filmed everything they could', Louise said. 'They interviewed Neil, they interviewed me and they made sure they got the general draggers of running the house'. We sat Neil in his wheelchair, a ventilator tube obscuring his face while his son

plays on the floor around him. We see him worrying about what questions Oscar will ask about his father in 10 and 20 years' time, and we also see Neil constructing a memory box filled with objects to remind Oscar of his father as he grows up a walker, a teacher, a father, a husband. It is clear that Oscar provided Neil with the strength to face the disease and keep going.

'Neil lived with the disease because of Oscar', Matthew said. 'He wanted to be his own person, a little person. Me? I wouldn't want to hang around. I could not touch my arms and face stop working. I couldn't put my mum and partner through it.'

As he deteriorated, Neil wished he could do more for his son and Louise. 'I miss the ability to give and receive to a certain extent a hug', he wrote on his blog. 'I think I need to be good at it too. All I can do now is raise my eyebrow or give a reassuring wink. Before me that this does not have the same effect.'

Neil and Louise began to have conversations about the end and about life for Louise and Oscar without him. 'Towards the end he sent me to Scotland, where my family are, to buy a house for his child. He couldn't say to me, "I want you to find someone else", but he did let me know you will find someone else.' That was the only way he could let it go.

Then, they both knew, was coming out. Louise had bought a clock that projected the time on to Neil's bedroom ceiling. 'I imagine it is my own personal countdown', Neil wrote. His line in the sand was speech: if he was no longer able to communicate, life would not be worth living. As even as my speech becomes inaudible, he wrote in one blog post, 'I

**I miss the ability to give a hug,' he wrote on his blog. 'I think I need to be good at it too. All I can do now is raise my eyebrow or give a reassuring wink'**

the sharing. Mother said, "and breakfast was my job-as was the whole toilet thing. Neil was able to have a good estimate because he had an arm of friends to help out."

Considering what we were going through, we had an amazing amount of good times, Louise said. 'We use our friends and family much more than we would normally have done, and Oscar was always surrounded by people.'

There were so many people who wanted regular updates about his condition that in July 2008 Neil allowed on the idea of starting a blog – he called it Plattitude – so which he could share his daily news. It would be, he wrote in his introduction, a tale of fun and laughs with a smattering of upset and devastation. At the beginning the blog was Neil's way of keeping in touch with those close to him, but as word spread and strangers began to read it, Neil realised that he could raise the profile of a misunderstood disease. The posts became much more frequent: from the end of December 2008, for the next two months, he posted almost every day. But even much physical discomfort he was in and what our his mood. If he couldn't manage a post, he would ask Louise to write one for him.

At first Neil typed the blogs himself. When that became impossible, he would ask whoever was in the house to help him, and also began using voice-recognition software. In one entry he described his changing reaction to his condition. Stage one was disbelief: 'I met with death in it was given the

to communicate demanded that we just got on with the job. The perfect crystallised when Dave and McKinnon decided to see words from Neil's blog to narrate the film. This empowered us, Dave said. Because it stripped the film from concentrating on his physical body and reminded us of the power of his mind.'

The resulting film, *I Am Breathing*, has already been screened in 14 countries, with many more to come. It is a powerful and moving film that is meeting its aim at 2014, at the airport with their son, Oscar, in June 2008, but with Oscar at his first birthday party in September 2010. **Below** had Neil Oscar in June 2008, on the day Neil first starting losing touch with the way Oscar had been brought up to start





## Health

**T**hey call it lock-in. When you have motor neurone disease (MND), you get locked into your own body because this condition doesn't affect your mental acuity, your sharpness of thinking or your memory. It's maddening. It doesn't dull your senses, so you can still feel pain like anybody else. If you were to stand on my foot, I would feel you standing on it, but I wouldn't be able to do anything about it.

It starts in different places for everybody. For me, it was in my feet – within a couple of days, I couldn't move my toes. On Christmas Eve 2007, I had an MRI scan which was absolutely clear, and that ruled out all of the easy things such as a trapped nerve. The consultant told me that, given my family had a history of MND (my father and grandfather both died of it), it was highly likely I had it.

I met my wife Louise at art college. We got married in 2004 and our son, Oscar, was born on 25 August 2007. So this was his first Christmas, and we didn't want to mar it. The whole family realised it was likely to be bad news, but because it hadn't been absolutely confirmed I think we all held out hope. It was only at the end of the following January that they ruled out all of those complicated but fixable things.

With MND, messages from the brain fail to reach your motor nerves. It crept up my body so I gradually lost the use of everything. When I lost the use of my legs, we had to get a hoist to help me stand. I was wheeled from room to room in this hoist and the same day we got it, Oscar pulled himself up on the bars of his playpen. When I first had to use a bottle to pee in, he started using his potty. When I got my wheelchair, he started using his walker.

There was always a good chance I would contract MND. I was 22 in 1996 when my dad died, and I was very aware of it from that point. With my dad and granddad it took six months from the onset of symptoms to death, without any kind of treatment. I was prescribed the only drug known to have any effect, riluzole. It's meant to delay the progression by three to six months or so. But when it starts to progress, it progresses quickly. Now, I've just got the use of my lower jaw and my eye muscles. I can't move my neck any more – speech and breathing are the only controls I have.

I wear patches for pain relief and I take pain relief tablets every day. If I didn't, I would feel all the aches and pains of muscles as they slowly stop working and shrink, joints that become unsupportive, my pelvis starting to



Neil Platt's battle with motor neurone disease is the subject of a new film. In his last interview before he died in 2009, published here for the first time, he describes his daily struggle

## Locked in my body

**Family first ...**  
Neil Platt with his son, Oscar

**People sometimes ask why we had a child when we knew he could get MND**

flatten, the ventilator hose wrapping around my head. Occasionally, I've had pain from my hips to my knees, down the side of my thighs. I felt like the skin had been ripped off my thighs, my feet had been dipped in boiling water and my fingers had been dipped in ice.

When every aspect of your life is shredded, you have to try to find pleasure somehow, in order to make each day possible and move on to the next. You can't cry, because every time you get upset your nose runs, you can't breathe properly and the ventilator gets full of saliva and mucus so it's difficult to swallow. If you get frustrated or angry, you can't move to

lash out, or shout. There's nothing you can do about it.

The biggest frustration for me is that if there's something that needs to be done, I can describe it so clearly but then people do something else. It's infuriating. You can learn to accept that you can't do things for yourself, but that doesn't belie the fact that you know you could do them better. Louise calms me. She and I practise reiki, which helps me relax. It takes me to a very deep, calm place sometimes. Then there are treats like taking a bath. When I'm in the hospice for respite care, the bath is one of the only places where we get to be completely alone.

Before we got married and had Oscar, we had a discussion about whether we should do either of those things. But the chances of me getting cancer or having a stroke or being hit by a bus were higher, so why should we hold back? People sometimes ask why we had a child when we knew he could get MND – I feel the same way about that as I feel about me getting it. It's really bad luck, but the chances of something else happening are far greater.

I certainly don't regret my 34 years on this planet and I hope MND is a problem that will be treatable and fixable one day. A new centre in Sheffield has just got planning permission. It's going to open when Oscar is about three and a half (the centre opened in 2010). That's 30 years of research to crack it before he's my age.

I don't think about dying as much as you might expect. It's not at the centre of my thoughts. It's secondary to making sure my family and friends are as prepared for it as they can be, by talking to them and being with them. I'm also making a memory box for Oscar to give him a sense of me. In it, there's my favourite leather jacket, which his mother hates, there are photographs of me, the original Jungle Book LP my dad bought me when I was a kid, a brass turtle I used to play with, the watch my mother gave me when Oscar was born. Things that define and describe me without showing anything down his throat.

Stephen Hawking has had this disease for 20 years – it's a unique, unexplainable phenomenon. But I wouldn't want to put my family and friends through this for the next 20 years. I want to see my boy grow up, but I don't want to watch someone else doing the things I should be doing. It was so difficult watching him take his first steps, holding someone else's hands.

Interview by Anne Wollenberg

**I Am Breathing** will be released on 21 June, MND Global Awareness Day. For more information, visit [iambreathing.com](http://iambreathing.com)



**C**ritics are not naturally the most emotionally engaged of people; and film critics in particular are rightly cynical about the ways directors attempt to manipulate the public's tear ducts. Nevertheless, at various moments during the press screening of *I Am Breathing* there were at times unmistakable sniffling noises in the invited audience... and I don't think it was just critics suffering from seasonal colds.

Perhaps this was not so surprising, given the film's subject and content. *I Am Breathing* is being screened in this country and worldwide this Friday, which is the Global Awareness Day for Motor Neurone Disease; and it is an intensely personal documentary covering the last weeks in the life of Neil Platt, a British architect who died at the age of 34 in 2009, after the disease had within two years reduced him from a vibrant and energetic man at the

**'I Am Breathing' is an intensely personal but not unrelentingly bleak documentary**

peak of life, to an inert shell unable to move a single muscle.

In the case of the Platt family, there was a tragedy beyond the fact that Neil had been stricken by a condition of progressive and dramatic neurological degeneration. His grandfather and father had been similarly afflicted: although around 5,000 people in the UK suffer from MND at any one time, only around 3 to 10 per cent of those are cases which have a genetic origin.

This was the main reason Neil Platt and his wife Louise invited the directors Emma Davis and Morag McKinnon into their home, to film his final months as the disease completed its dreadful final assault on his physical being (it has no effect on cognitive faculties). They had a child, Oscar, just one year old at the time Neil's overwhelming desire was that somehow a cure might be found that would give his son a chance, should he too fall victim.

So not only is the film itself designed to raise public awareness of this condition – of which Professor Stephen Hawking is the most well-known sufferer: all the revenues from the global screenings this week will go into MND research and development, if readers want to get involved in this project themselves, the website [www.iambreathing.com](http://www.iambreathing.com) gives all the necessary details.

Currently in the UK, only about £2m a year is devoted to the funding of research into MND, which may reflect the relative small number of people affected – so

# A dying man who reminds us just what life is for



fly-on-the-wall documentary, unbearable though it is in its most final moments as Neil Platt struggles desperately to breathe. "He never wanted to die. He went kicking and screaming," says Louise. There are also moments of almost sublime black humour, most notably when Neil, putting the family's financial affairs in order, describes his attempts to terminate the telephone line rental. Even after he explains to the call centre his reason, he is asked: "Can we offer you an extra three months for free, Sir?" As he replies, *dealplan*, that was a better deal than any of his doctors could come up with.

**T**his reminded me a little of what it was like when one of my sisters was dying of cancer, at the age of 32. Humour became more important than ever, not just as a necessary distraction, but also because what was happening was almost unbelievable and therefore surrounded by absurdity. And yet, as each day went past, the light from the dying got smaller and the darkness bigger. This aspect of a young family approaching death's imminence is communicated with complete integrity in *I Am Breathing*: an integrity that is only enhanced by the refusal to witness the moment of death itself.

That is because, unlike the more fashionable documentary makers' topic of so-called assisted suicide, this is not a film about death. It is a film about life. The right response, or so it seemed to me, is not to come out of the cinema crying, but to feel grateful for life's gifts, which can be so randomly snatched away. That must be why the film records Neil dictating his blog ("Plattitude") into a voice-activated computer, for posterity: "My acquaintance with the when of things has confirmed how right I was to have an awareness of and value my time. You could all do me a favour – don't let yours slip by unnoticed."

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pared with various forms of cancer, for example: but given that the condition was first identified back in 1874 it is somehow shocking that there is not only no cure or treatment – medical science does not even know what causes the disease.

Perhaps if it affected children or younger people, there would be more attention paid, but most typically it attacks people – mostly men – in later middle age: Neil Platt's case was unusual in the earliness of its onset. Indeed, the poignancy of the film is somehow increased by the fact that Neil was, even as he became inert, startlingly handsome. Perhaps one shouldn't admit to this thought, but there is something especially incongruous in seeing a physically beautiful young man being spoon-fed by his wife and unable to hold or hug his tiny son.

His wife Louise – nursing both her son and husband – speaks of how "cruel" it was

that Neil was degenerating at exactly the same time as Oscar's physical coordination was developing naturally: "I would find it even more sad to see almost the same thing happening in the opposite direction with Neil at the same time. I started having to spoon-feed Neil just as the spoon was being grabbed off me by Oscar."

Yet the person in the film whose predicament seemed to me most unbearable is Neil's mother, Lynne. Her son, perhaps wanting not to know the truth, seemed slow to realise the onset of MND, when it first manifested itself with what he described as "my right foot flapping a bit... I thought that I needed a new pair of shoes". Yet when his mother saw him limping as he walked towards her at a railway station, she knew, instantly. It was exactly the same way her husband had limped, before anyone had diagnosed him with MND.

Yet this is not an unrelentingly bleak



<http://www.dailymail.co.uk/health/article-1102803/He-thought-hed-avoided-disease-killed-father-But-Neils-joy-sons-birth-turned-painful-anguish.html>

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## 'My son's kiss makes life worth living': The heartbreaking story about a 34-year-old father's race to provide a legacy for his child before he dies of motor neurone disease

- Neil Platt was diagnosed with the degenerative condition in 2008 aged 34
- Within just months he was unable to move or breathe without the help of a ventilator and he died a year later in February 2009
- 'I Am Breathing' captures his last few months of life, showing how the disease ravaged his body but it also highlights his indomitable spirit
- The film shows how Neil writes a letter for his now six-year-old son
- Letter gives manly advice and a memory box contains Neil's favourite leather jacket and hat, his childhood teddy bear and a Zippo lighter
- Neil wanted to raise awareness of MND so that a cure can be found
- The film ends with Neil's death

By MICHELLE KOSLOFF

PHOTO: GETTY IMAGES

sleeping against the ground when he awoke. He grew increasingly concerned that he was developing the same condition that had killed his father when he was 51, and his grandfather had undergone a rift of bone and all the results came back clear, but had knew that his symptoms were not normal.

2000

- Teenager, 16, started carrying PVR money and was told not to. Had \$100, just weeks later was dead of overdose
- Her using her parents' surname after he decided from responsibility to find the police have had been

Eventually he was referred to a neurologist who, taking his family history into account, broke the shattering news to the new father. It is not possible to test for MHO specifically – it is only diagnosed after a process of elimination.

Check the following New Frontiers. The Green Book issue leaf's lists with accompanying sound



A heart-rending film about a young father's battle with motor neurone disease and the letter he struggled to write to his two-year-old son in his last months as he is released over the month.

1. **Ask (inspiring or heartbreaking) the last months of former prisoner** **Paul's** life. Viewers are given an insight into how the **prisoner** ravaged his body but the docuser also celebrates the 34-year-old's remarkable story.

has documented the rapid and steady decline to raise awareness of the neurological disease so a cure could be found as soon as possible – and hopefully before his son, who is also at risk of developing the deadly condition, grows up.

Sendt down for the trailer



and that is consistent with the fact that the first two months of the year are the most difficult for the company.

had been diagnosed with HIV in February 2008. Months before, he had noticed that his body was



The speed that the disease took over Neil's body was staggering. Neil is pictured with his first two-year-old son, Oscar, just 6 months after his diagnosis and three months before his death.

He quickly lost the use of his hands and legs and the couple were forced to move from south London to North Yorkshire to be close to Ina's family who could help care for him.

By Oscar's first birthday, Neil had lost the use of his entire upper body and required a ventilator to push air into his lungs because their capacity had plummeted to just 30 per cent.

He was also forced to give up work because not only had his hands stopped working but the

She said at the time, 'Life seems to work in one way: the week Oscar joked up his sport to beat himself, I had to start leading fast because he could no longer off a track.'

1. Air breathing follows fish's final months, unable to move without the help of family. Parents and a specially-suited school

While he still has the ability to speak he reflects on his tragic situation and, with the help of his wife Julia, together a letter and memory box for his son Caesar.



BBC NEWS ONLINE

16<sup>th</sup> June 2013

Interview with Morag McKinnon and Emma Davie

<http://www.bbc.co.uk/news/entertainment-arts-22820046>



THE SCOTSMAN

13<sup>th</sup> June 2013

<http://www.scotsman.com/the-scotsman/scotland/i-am-breathing-a-dying-father-s-film-for-his-son-1-2963942>





# Features & Analysis

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## Neil's determination to tell his story as a cruel disease took its pitiless course



He called it a tale of fun with a smattering of upset and devastation. **Tony Earnshaw** reports on Neil Platt's brave film of life and death with MND.

IT'S rare these days to see a man as young as Neil Platt (1970), who has a rare form of motor neurone disease (MND), tell his story in a film. But he has done so in a way that is both brave and beautiful. His film, *Neil Platt: A Tale of Fun*, is a testament to his determination to tell his story as a cruel disease took its pitiless course.

Neil's story is a tale of fun with a smattering of upset and devastation. He has a rare form of motor neurone disease (MND), which is a cruel and devastating condition. But he has not let this stop him from living his life to the full. He has a sense of humour and a determination to tell his story as a cruel disease took its pitiless course.

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NEIL PLATT, with his wife and children, in a scene from his film *Neil Platt: A Tale of Fun*. The film is a testament to his determination to tell his story as a cruel disease took its pitiless course.

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## The wild bunch... a family who made life an adventure



Ever wanted to know how to build the perfect campfire or the best way to skin a rabbit? Just ask the Glastonbury family. Lisa Salmon reports.

IT'S a rare sight to see a family of five, with a young child, in a tent in a field. But for the Glastonbury family, it's a way of life. They are a family who made life an adventure.

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**“A MAN OF ACTION, A DOER. HE WANTED TO REACH OUT WITH ALL THAT HE HAD LEFT...”**

**With extraordinary humour and bravery Neil Platt wanted to show the world what MND means. The result is an exceptional film, *I Am Breathing*. Adam Forrest reports**



**N**eil Platt returned home one evening in October 2007 and took off his shoes and socks. He noticed he could not properly lift the toes on his right foot and told his wife Louise it felt a bit like the foot was “slapping itself” to the ground.

Louise sought to reassure her husband: he probably just needed a new pair of shoes. Yet Neil, knowing his family history, began to fear the worst. Motor neurone disease (MND), the terrible illness that destroys nerve cells allowing muscles to move, had killed his father at 51 and grandfather at 64. Neil, after several appointments with doctors and specialists, was finally diagnosed with the disease on February 7, 2008.

And so began a new life, coping with and managing the terminal condition. Neil and Louise were also adjusting to the joys of parenthood – their son Oscar had been born back in August 2007. Neil started writing a blog to keep loved ones informed about how the young family were getting on.

As his condition deteriorated, he became determined to share his experience as openly and widely as possible, deeply frustrated by how little was known about MND, how little was spent on research (just £300m a year) and how limited the pain management was (the drug Riluzole can slow deterioration and extend life by, at best, about six months).

Film-maker Morag McKinnon had been friends with Neil and Louise since they studied together at Edinburgh College of Art, and Neil was keen to create a document of his battle with the disease, a fight for as much time as possible to spend with wife and son. “To go back to the house



as part of the film crew, it was emotionally difficult and a huge learning curve for me,” Morag recalls.

“You’d want to go and do something practical as a pal – to do the dishes, say – and I had to be trained to think differently. Filming everything was important to him – he wanted to open up to the world to show the effects of this terrible disease. He called the shots in that sense. He was a man of action, a doer, and I think it was honourable and brave of him to deal with everything so practically and with such humour.”

Co-director Emma Davie, an experienced documentary-maker, was initially wary about filming the Platt family at a time of such vulnerability. But after going to meet Neil at the Platts’ home in Harrogate, she understood how much he wanted to share.

“The force of his personality was such that it just felt like the film had to happen after that,” she remembers. “It had a life of its own. He was a man who had a need to communicate and he managed to communicate with such force and humour.”

Neil Platt died, aged 34, in February 2009. He was cremated wearing a Chuck Norris T-shirt, and the song he requested – Bon Jovi’s *Wanted Dead or Alive* – was played at the service.

His wish to create a powerful record of his final months was also granted. The resulting film, *I Am Breathing*, will be shown at more than 100 screenings across more than 25 countries around the world on June 21, which is MND Global Awareness Day. Fifty per cent of the profits will be donated to the MND Association, the other half invested in outreach work.

“Having the film as a legacy means that the effort Neil made to raise awareness for MND in his final months didn’t stop when he died,” says his wife, Louise. “He wanted to reach out with all he had left, his voice – the film is going to do that for him, reaching far wider than he ever imagined.” ●

*I Am Breathing* will be screened internationally on June 21, MND Global Awareness Day, which will also launch the UK cinema release. Set up your own screening and raise money and awareness for MND through [iambreathing.com](http://iambreathing.com)



The Daily Record and Sunday Mail  
16<sup>th</sup> June 2013



<http://www.dailyrecord.co.uk/news/real-life/mans-tragic-death-motor-neurone-1956083>



LOOK MAGAZINE  
Tuesday 18<sup>th</sup> June 2013  
Interview with Louise Oswald

LOOK



## I Am Breathing

United Kingdom/Denmark/Finland 2012  
Directors: Emma Davie, Morag McKinnon



Remarkable determination: Neil Platt


### Reviewed by Trevor Johnston

Strange how the apparent intimacy of the video-diary form sometimes proves unexpectedly distancing. This striking documentary about a 33-year-old Scots architect struck down by the ravages of Motor Neurone Disease is a case in point. Neil Platt, an old student-days acquaintance of the filmmakers, invited the camera in to share his final months, showing remarkable determination to turn the course of his demise into a campaigning exercise – in conjunction with his revealingly honest and witty blog, *Plattitude* – hence raising awareness of the incurable condition that had also taken his father's life years previously.

The access-all-areas result captures the ordinary and the extraordinary in Neil's unfolding circumstances: he's cared for at home by his indefatigable spouse Louise while the couple's small son Oscar toddles around; the intrusion of a hospital-grade hoist, ventilator and recliner marks a stark juxtaposition with the routines of domesticity. Sheer coincidence throws up telling moments, like the TV talent-show hopeful in the background belting out 'The Impossible Dream', yet even as we're struck by the purposeful level-headedness and astonishing lack of self-pity Neil displays as his time peters out, we could conceivably feel insulated from the images by their sheer raw particularity. Thank the heavens it's happening to him, there but for the grace of God...

That's not meant in any way to disparage the impact of sequences such as the harrowing footage of Neil struggling for every last breath – moments surely indicative of a deep bond of trust between subject and filmmaker. Instead, it's proffered as a way of commending co-directors Emma Davie and Morag McKinnon for their key insight that this fly-on-the-wall footage wasn't sufficient in itself to convey the totality of their obvious ambitions for the film. Yes, it's a portrait of heartbreaking courage, but when it stops looking at Neil's heroic struggle and begins to recreate his emotional and imaginative journey from the inside, that's when it becomes so much more – a haunting and inclusive encounter with the all-encompassing verities of time, experience and mortality. By layering in old home-movie footage of Neil's and Louise's

honeymoon, for instance, the filmmakers convey for us the flood of memories occasioned by the shockingly aggressive progress of his illness, while POV images of the effect of the seasons on the couple's suburban garden also place Neil's awful fate within the natural world's broader cycle of decay and renewal. The masterstroke, though, is the incorporation of travelling footage shot on country roads, which magically unites the particular and the universal, since it subjectively signifies Neil's own memories of riding the motorbike he loved (resonating also with the terrifying possibility that his MND may have been a reaction to a bee sting he received while out on a ride) while also metaphorically registering the notion of a journey with existential and maybe even spiritual associations.

Editor Peter Winther and senior editing consultant Janus Billekov Jansen have between them done a marvellous job of making sure that all these elements get just the right amount of screen time, integrating them with a fluidity which gives this genuinely powerful film a masterly assurance. It's perhaps a hopeful presumption that the 'I' in the title might refer to the viewer as well as Neil the subject, or indeed that we might take to heart Neil's onscreen blog entry suggesting that his personal realisation of "the when of things" should be an encouragement for us not to let our own time "slip by unnoticed". Yet that's precisely how the film plays out, its astute overall conception of the two-way traffic between the intimate and the cosmic giving *I Am Breathing* a sustaining hold on our thoughts and consciousness long after the tears we shed for Neil have melted away. 

### Credits and Synopsis

<b>Producer</b> Sonia Henrici	Danish Documentary Production	Scotland, Channel 4, Wellcome Trust, MND Association, DR
<b>Edited by</b> Emma Davie	Supported by Creative Scotland, Danish Film Institute	- Danish Broadcast Corporation, YLE Broadcast Corporation, UK Film Council Lottery
<b>Editor</b> Peter Winther	In association with Channel 4, Wellcome Trust, MND Association, DR	<b>Executive Producer</b> Noë Mendelle
<b>Composers</b> Kieran Hebden Jim Sutherland	- Danish Broadcast Corporation, YLE - Finnish Broadcast Corporation	<b>In Colour</b> [1781]
<b>Sound</b> Morag McKinnon	Made with the support of UK Film Council	<b>Distributor</b> Scottish Documentary Institute
©SDI Productions Ltd./Danish Documentary Production ApS	In co-operation with DR International	
<b>Production Companies</b> SDI Productions/Scottish Documentary Institute	Sales Developed and supported by National Lottery through Creative	
In co-production with		

A documentary portrait of Scottish architect Neil Platt, diagnosed with Motor Neurone Disease in 2008 at the age of 33. Knowing that his condition will soon rob him of speech and movement, he begins a blog, collaborates on this film and puts together a memory box for his infant son Oscar. He recalls good times with friends and family, who rally around as he's cared for at home by spouse Louise. Meanwhile his increasingly high-profile online presence provides an outlet for his feelings and a vehicle for raising consciousness about Motor Neurone Disease, still untreatable despite medical advances in other areas. Eventually Neil's condition worsens; he completes his final blog entry and spends his last days in a hospice with Louise. He passes away in February 2009.





## ONLINE REVIEWS

### **RADIO TIMES**

<http://www.radiotimes.com/film/w6x7k/i-am-breathing>

### **HOT MINUTE MAGAZINE**

<http://www.hotminutemag.co.uk/2013/06/i-am-breathing/>

### **BEST FOR FILMS**

<http://bestforfilm.com/film-reviews/i-am-breathing/>

### **I FLICKS**

<http://i-flicks.net/blog/1-latest-news/3982-i-am-breathing-plans-global-screening-day>

### **VIEW LONDON**

<http://www.viewlondon.co.uk/films/i-am-breathing-film-review-52836.html>

### **UK FILM NETWORK**

[http://ukfilmnetwork.com/magazine/read/scottish-documentary--institute-presents-i-am-breathing\\_241.html](http://ukfilmnetwork.com/magazine/read/scottish-documentary--institute-presents-i-am-breathing_241.html)

### **DISABLED AND SUPPORTIVECARER**

[www.disabledandsupportivecarer.co.uk/film-charts-dads-personal-story-to-raise-global-awareness-about-mnd](http://www.disabledandsupportivecarer.co.uk/film-charts-dads-personal-story-to-raise-global-awareness-about-mnd)

### **ARCHITECTS JOURNAL**

<http://www.architectsjournal.co.uk/news/daily-news/heartbreaking-film-about-dying-architect-to-premier-in-uk/8649104.article>

### **GROLSCH FILM WORKS**

<http://grolschfilmworks.com/ca/reviews/i-am-breathing>

### **CELLULOID HEROES**

<http://celluloidheroes.co.uk/review-i-am-breathing/>

### **LONDON CITY NIGHTS**

<http://www.londoncitynights.com/2013/05/i-am-breathing-2013-directed-by-emma.html>

### **SCREEN INVASION**

<http://screeninvasion.com/2013/06/eiff-2013-i-am-breathing-movie-review/>



**EMPIRE**

<http://www.empireonline.com/reviews/review.asp?FID=138199>

**THE UPCOMING**

<http://www.theupcoming.co.uk/2013/06/17/i-am-breathing-movie-review/>

**THE SKINNY**

<http://www.theskinny.co.uk/latest/304897-eiff-2013-i-am-breathing>

**MOVIE MAIL**

<http://www.moviemail.com/blog/cinema-reviews/1526-I-Am-Breathing-on-the-life-and-death-of-an-architect/>

**BRITFLICKS**

<http://www.britflicks.com/review.aspx?filmid=527>

**BEST MAGAZINE**

<http://www.bestdaily.co.uk/your-life/news/a490652/i-am-breathing-heartbreaking-new-film-about-motor-neurone-disease.html>

**CANDID ONLINE**

<http://candidonline.com/review-i-am-breathing/>

**THE FAN CARPET**

<http://thefancarpets.com/reviews/iambreathing/>

**ENTERTAINMENT.IE**

<http://entertainment.ie/movie-review/i-am-Breathing/194187.htm>

**MSN**

<http://now.msn.com/i-am-breathing-film-follows-a-fathers-last-months>

**CINE VUE**

<http://www.cine-vue.com/2013/06/film-review-i-am-breathing.html>

**BOX OFFICE BUZ**

<http://reviews.boxofficebuz.com/review/i-am-breathing-movie-review>

**DEREK WINNERT**

<http://derekwinnert.com/i-am-breathing-film-review/>

**FEMALE FIRST**

<http://www.femalefirst.co.uk/movies/i-am-breathing-review-297873.html>

## FILMORIA

<http://www.filmoria.co.uk/2013/06/i-am-breathing-review/>

## RTE

<http://www.rte.ie/ten/reviews/movies/2013/0620/457552-i-am-breathing/>

## CLOSE UP FILMS

<http://www.close-upfilm.com/2013/06/i-am-breathing-e-close-up-film-review/>

## ABOUT

<http://documentaries.about.com/od/revie2/fr/I-Am-Breathing-Movie-Review-2013.htm>

## THE FILMMAKERS

### Emma Davie, Director

Emma is a documentary filmmaker and Programme Director of Film & TV at Edinburgh College of Art, University of Edinburgh. Previous work includes *What Age Can You Start Being An Artist?* for Channel 4 (2004, nominated for Grierson Award); *Gigha: Buying Our Island* (2002), a one-hour film for BBC/Scottish Screen; and *Flight*, a BBC/Canadian co-production (2000).

Emma's background in experimental theatre and performance gave her a love of collaborative practice. She worked with, amongst others, Robert LePage on *Tectonic Plates* but also ran her own company *Clanjamfrie* which did huge large-scale site-specific performances. She was on the board of the European Documentary Network (EDN) and writes for DOX magazine. She has worked as tutor or consultant with EDN, European Film College, Storydoc, Discovery Campus, East European Forum, Docs Barcelona, and many others.

### Morag McKinnon, Director

Morag is a fiction director whose most recent film *Donkeys* won a Scottish BAFTA in 2011 for Best Feature. It was the second part in the Scottish/Danish co-production with Lars von Trier's company – the follow up to *Red Road*.

Prior to that, she has directed award-winning series and shorts including the BAFTA-winning series *Buried* (2004) and the short film *Home*, which also won a BAFTA for Best Short and 16 international awards including the Fox Searchlight New Talent Award. Her other award-winning short, *Birthday* (2001) won the Silver Bear at the Chicago Film Festival. Morag is a graduate of Edinburgh College of Art.

## ABOUT SCOTTISH DOCUMENTARY INSTITUTE

**Scottish Documentary Institute** is a documentary research, production and distribution centre at Edinburgh College of Art, University of Edinburgh.

It was set up in 2004. Our aim is to stimulate and inspire the documentary scene in Scotland and beyond through focus on creative excellence and clear international outlook. We also work at bridging the gap between academia and industry. Our films have played at major film festivals, such as Sundance, Cannes, Hotdocs, Tribeca, Full Frame, Silverdocs, IDFA, Cinéma du Reel, Vision du Réel, Leipzig and have picked up major awards and nominations.

[WWW.IAMBREATHING.COM](http://WWW.IAMBREATHING.COM)

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*"If I am to turn this mild spring breeze of a campaign into the wind that uprooted trees and demolished houses, I am really going to need your help"* **Neil Platt**

MND/ALS GLOBAL AWARENESS DAY 21 JUNE

I AM BREATHING