

## THE WOLF INSIDE

A young actress's fight against lupus

(*You*, 2008)

In the autumn of 2002, N'Deaye Ba was to all appearances a deeply enviable young woman. The beautiful 30-year-old actress had recently married her director boyfriend; together they had bought a new house in Bristol, where she was to spend the next six months filming *Casualty*. But on the day of their move, N'Deaye received the results of a blood test showing that she had contracted a little-known disease called lupus. It was the beginning of a two-and-a-half-year battle which would cost her her looks, her marriage and ultimately her life.

N'Deaye, however, left a remarkable legacy. As the disease took hold, she and her mother Christina decided to make a documentary about her experience of it. Neither had directed a film before, and their only piece of equipment was a home video camera; but when a preview of *The Wolf Inside* was shown at BAFTA earlier this year, it received a standing ovation. Among those who queued up to congratulate Christina afterwards was the veteran director Mike Leigh. 'He asked me to send him a copy,' she says. 'Perhaps he will draw on it for one of his own films. I hope so.'

N'Deaye's aim, she explains, was to bring an understanding of lupus both to the general public and to a medical profession which she sometimes found shockingly ill-informed. 'She was often mistaken for a hypochondriac,' says Christina. 'On one occasion she went to the doctor and he said with a long sigh, "What's the matter with you today? I've only got ten minutes."'

Lupus is a condition in which the body's immune system turns against itself and attacks healthy blood cells. (The name – Latin for 'wolf' – derives

from a distinctive rash which covers the nose and cheeks in a shape like a wolf's mask.) The causes are unknown, but it has been found to affect nine times as many women as men, especially those with African antecedents. (N'Deaye's father is Senegalese.) It can affect the joints, the internal organs and the skin; in N'Deaye's case the symptoms were a swelling of the face, legs and stomach which left her unrecognisable. But because these symptoms come and go, and resemble those of quite different diseases, lupus often escapes detection.

'For most people, if treated in good time, it isn't life-threatening,' explains Angie Davidson, who runs the Lupus Trust at St Thomas's Hospital in London. 'The problem is that it takes on average four years to get a diagnosis.'

What makes *The Wolf Inside* doubly extraordinary is that Christina too was suffering from a life-threatening disease – chronic lymphatic leukaemia – while filming it. But the documentary is not just about illness: it also chronicles with unflinching honesty the relationship of mother and daughter, with its outpourings of love and frustration, as they face the prospect of losing each other.

Christina Johansson was a rebellious 21-year-old when she met and married N'Deaye's father in her native Sweden in 1971. Their daughter was born the following year, but the marriage soon ended, and Christina was left to bring up N'Deaye on her own. Their move to Britain came in 1992, when N'Deaye – realising that there were more opportunities for a coloured actress here than in Scandinavia – decided to apply to drama school in London. So enthusiastically did she embrace her adopted country that within a few years she and her mother were talking to each other in English rather than Swedish.

Life was tough at first ('We had to work night and day to earn enough money for her fees,' remembers Christina), but when N'Deaye graduated

from the Webber Douglas Academy in 1996 she found no shortage of agents wanting to represent her. She went on to appear in several prime-time television series, including *Trial and Retribution*, *Sea of Souls* and *Jericho*.

An attempt to establish herself in Hollywood was less successful. ‘She got some work, and mingled with the famous people [a snapshot shows her posing with Laurence Fishburne], but it was a struggle,’ says Christina. ‘She was very down-to-earth, and didn’t want to change her teeth and hair. It just wasn’t her scene.’

While in Los Angeles, N’Deaye began to feel the first effects of lupus, suffering from swollen limbs and a series of infections. But these symptoms were short-lived, and what most concerned her on her return to London was the discovery that her mother had contracted leukaemia. Christina believes that the resulting stress aggravated N’Deaye’s own condition.

‘In autumn 2002, her personality began to change,’ she says. ‘She became very tired and very anxious about the future. From being one of London’s biggest party girls, she began to withdraw from her friends and become very isolated.’

N’Deaye’s first major crisis came just before Christmas that year. ‘She was taken into accident and emergency at Southmead Hospital in Bristol, and was found to have kidney failure. She stayed there for a week on high medication. Her face was so swollen that it could not be recognised.’

But after New Year the symptoms subsided, and as luck would have it, such flare-ups never coincided with the times when N’Deaye was filming. ‘She decided immediately to keep her illness a secret,’ says Christina. ‘She didn’t want to have to keep explaining her condition, and she also said, “I won’t get any more jobs in the film industry if people know.” So she only told me, her husband and one close friend.’

N'Deaye's had married her husband, Jonathan Clements, in Somerset the previous June; the party lasted for two days, and so exuberant were the celebrations that the bride and groom forgot to cut the wedding cake. Perhaps it was an omen, for within three months of N'Deaye's hospitalisation, their relationship had ended. But if Christina feels reproachful towards her former son-in-law, she is slow to show it. 'Anyone who suffers from lupus needs a very understanding family,' she says simply. 'A lot of sufferers that I've talked to have had their marriages break down.'

*The Wolf Inside* begins in the summer of 2004, after a year in which N'Deaye veered backwards and forwards between apparent health and acute illness. 'It's almost like there's something inside you that can turn on you at any time,' she says on camera. 'When an attack is coming, your whole body just breaks down. You can almost feel it happening.'

What will immediately strike anyone watching the film is the combination of courage, determination and humour with which N'Deaye faces her sickness. 'I'm going to try everything I can try, and I'm going to go to the ends of the world...' she declares. 'I have to beat this thing, and I'm going to beat it, and I'm going to be strong again.' One might expect a woman with such exceptional looks to be devastated by the sight of her face turned swollen and blotchy by the disease, but instead she jokes, 'It's just fabulous: I'd recommend it to anyone who's bored with their appearance. Get lupus get it fast, and enjoy every minute of it.' ('N'Deaye was never vain,' remarks Christina. 'She never looked on herself as a beauty.')

This is not to say that there are no moments of despair. One of the worst comes when N'Deaye's disease flares up just as she is about to move to Stratford for a fourteen-month stint with the Royal Shakespeare Company: forced to forego the chance of a lifetime, she weeps and turns from the camera to hide her face under a blanket.

The film also captures Christina in some of her darkest moods – in particular, those brought on by arguments with her daughter. A more egotistic director would surely have edited out an episode in which her daughter accuses her of being manipulative; but there is Christina, struggling through her tears to justify herself. ‘I know all the anger in you, that you are ill, must go out over somebody,’ she says. ‘And I can take that. But I can’t take [the fact] that you think I’m manipulating and bad...I’m so, so afraid to lose you.’ It is this raw honesty which makes the film so compelling.

But *The Wolf Inside* is also a spiritual journey, and although it spans less than a year, there is a strong sense of N’Deaye (who – with Christina – converted to Buddhism in 2003) arriving at a new knowledge of herself. ‘After all the partying, she tried at the end to find the true meaning of life,’ says Christina. ‘She was far deeper than I am. Robert Lindsay [the star of *Jericho*] said to me, “When N’Deaye looked into my eyes, I realised she was looking into my soul.”’

N’Deaye died in April 2005, with her mother by her side. Three years later, it is clear that Christina – who now lives in the Swedish town of Trollhättan – has still not come to terms with her loss. ‘I’m sorry,’ she says, wiping the tears from her face, when we meet on one of her rare visits to London. ‘Coming here brings back so many memories, good and bad.’

After N’Deaye’s death, she explains, she found the city where they had lived together almost unbearable: ‘So I did something I’d told myself I never would, and moved back to Sweden. I lived for one year completely isolated by the sea, just working on the film, which of course was very painful. Then in autumn 2006 I got really ill and had to go on chemotherapy, but I was determined to pull through. I had promised to fulfil N’Deaye’s work, and I couldn’t bear to think that it might just end up in a drawer.’

The film's final preparation was overseen by Ben Gooder, a producer for whom Christina had worked as a nanny when she first came to London. 'I was fascinated by the idea that N'Deaye had decided to commit her story to video without knowing where it would lead,' he says, 'and by the honesty of the method. I was worried that the technical quality might not pass muster, but the content was so powerful that it seemed to justify it.' *The Wolf Inside* has been sold to Swedish television, and Gooder hopes that a buyer will soon be found in Britain as well.

Christina – who is still receiving treatment for leukaemia – has now started work on a book about N'Deaye, drawing on her daughter's hospital diaries. (She has already edited a collection of N'Deaye's poems, *My Butterfly Secrets*.) 'The grief I feel comes from a dark place deep, deep inside where I have never been before,' she says. 'But in the middle of it all there is a gratitude to the universe that N'Deaye came into my life. She gave me love, joy and amazing memories, and without her my life would have been worth nothing. I fulfilled this film in my daughter's name and for everyone else who suffers from lupus, because N'Deaye didn't do this for herself: she did it for the world.'

*For more information about lupus, contact St Thomas' Lupus Trust (020 7188 3562; [www.lupus.org.uk](http://www.lupus.org.uk)). To order a copy of 'My Butterfly Secrets' visit [www.ndeayeba.com](http://www.ndeayeba.com)*