

## **'I am valued here': the extraordinary film that recreates a disabled boy's rich digital life**

Cath Clarke, *The Guardian*, 22 Oct 2024

Mats Steen had muscular dystrophy and died very young. But a touching new documentary has used animation and his own posts to reveal the fulfilling gaming life he led in World of Warcraft

Mats was born with Duchenne muscular dystrophy, a progressive condition that causes the muscles to weaken gradually. He was diagnosed aged four and started using a wheelchair at 10. By the end of his life, Mats could only move his fingers, and required a tube to clear his throat every 15 minutes. As he became increasingly disabled, he spent more time gaming: 20,000 hours in his last decade (about the same as if it were a full-time job).

His parents wondered how they could share the news of his death with his online acquaintances. They didn't have access to his World of Warcraft account, but his Dad found the password to Mats' blog, and they wrote a post. It began: "Our beloved son, brother and best friend left us this night ..." But, they wondered, would anyone read it?

They were stunned by the response. Emails started pouring in from around the world: "Mats' passing has hit me very hard." "Mats was AWESOME." "You should be proud of your son." "Mats was a real friend to me." The couple had been anguished that Mats' existence was lonely, that illness had isolated him, but here were messages, some pages long, from his close friends on World of Warcraft.

Mats made close friends online and touched their lives. But for years he hid his illness in World of Warcraft, a place where he wasn't defined by disability. "Games are my sanctuary," he wrote. "I am safe here, valued." But in the summer of 2013 he started the blog, which he did eventually share with some of his gaming friends.

*The Remarkable Life of Ibelin* arrives at a time when parents are agonising over how much screen-time to give their kids. Because of his disability, Mats' parents let him spend more time gaming than other children. He was on his Game Boy during breaks at school while other kids played football.

The film director took an almighty risk making the documentary. He worked on it for three years before approaching Blizzard, the company that owns World of Warcraft, for permission: "We wrote them an email, 'We are a small Norwegian production company. Could we have the rights for free?' The Blizzard bosses invited him to California to screen Ibelin at their offices. "I had to take extra doses of asthma medicine before the meeting," Rees says with a grin. But like everyone else, the bosses finished the film in tears.