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43 YEARS IN AN IRON LUNG

John Prestwich lives just minutes from death. Paralysed, unable even to breathe, a mechanical ventilator keeps him alive. If it fails, John will be unconscious within three minutes and dead within five. His ventilator gives him 1,000 breaths an hour, eight-and-a-half million a year and over 350 million since he contracted polio on his 17th birthday in November 1955.

Some might expect this to be a sad story. It isn't. Despite his disability John leads a busy and rewarding life. He and his wife Maggie frequently attend their favourite sport, polo, and John regularly communicates with people all over the world by phone, fax and on the Internet. Forty years ago he couldn't even call a nurse.

Early in the morning of November 24, 1955, *Herdsmen*, a ship of the Merchant Navy, docked in Corpus Christi, Texas. Serving aboard was a young 17-year-old English seaman, John Prestwich. John was helping prepare the ship for unloading when he began to feel unwell. He reported sick to the first officer, went back to his bunk, and fell asleep. When he woke up, he couldn't lift his face off the pillow and was suffocating. Somehow, he managed to move his head slightly. The movement saved his life, but was the last he ever made. He woke up in the hospital in Corpus Christi, in an iron lung, hopeless and helpless. There he remained, desperately ill until March 1956 when the US air force flew him home.

He was admitted to the Royal Free

Struck down with polio at 17 and confined to a respirator, that could have been it. But John Prestwich had other ideas

Hospital in London, where the first two years were critical. "I wasn't expected to live. I was ill for a long time." He recalls lying in his "lung" when everything began to go quiet, dark and comfortable. The incredible pain began to subside. "I think I was on the way out. I remember lying in this room with an open fire at one end. I didn't want to give in, I was interested in what was going on tomorrow. Some of us are more bloody minded, I suppose."

Maggie Biffen had been working as an Occupational Therapist in the USA and Canada before she arrived at the Royal Free. She remembers their first meeting: "John was in an iron lung with only his head sticking out," she says. "It looked just like a coffin on legs." Part of Maggie's new job was to provide John with "Diversional Therapy". Maggie began to read to John, write his letters and occasionally help with his dressing and outings.

Over the next few years their relationship evolved. They began to fall in love and it frightened John. He saw

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John and Maggie Prestwich with celebrities, from left: Kirsty Young, Bob Hoskins, Lulu, Anthea Turner, Honor Blackman and Jeff Banks – a far cry from the merchant seaman's arrival home in 1956 age 17 in an iron lung after he was struck down with polio in Texas

For the last 26 years, they have been completely independent. John has a specially modified bed that also serves as a wheelchair. Beneath it are mounted a respirator and batteries so he can travel. They have a converted minibus, and take regular outings to friends, shopping and to watch their favourite sport, polo. Until a few years ago, the power to weight ratio of batteries was such that for only a few minutes of umbilical detachment, large and heavy batteries had to be mounted on John's bed to power the respirator. Outings consisted of short "leap-frog" forays between home, van and anywhere that mains power was available. This restricted John to just a few minutes of relative freedom. But battery technology has evolved and earlier this year, John was able to enjoy a prolonged picnic away from a ►

himself, paralysed and peniless, with and nothing to offer this, as he describes her, "bright, intelligent and articulate girl".

Thoughts of marriage never entered their minds until 1971, when John's uncle made a deed of gift to him. It enabled John to leave hospital. But no one with such severe disability had ever entered into marriage. No one who required such critical constant care had entrusted his or her life to one woman. On December 11, 1971 they were married at St Paul's Church in Chipperfield, Hertfordshire.



Hulton Getty

◀ power source.

Back at home, John controls much of his environment by a series of whistled codes, detected by a microphone, and converted by a computer into actions. This way he can control the television, video and hi-fi, open and close curtains and turn lights on and off. He makes and receives telephone calls. A video camera lets him see who's at the front door, and an electronic lock lets visitors in. He uses a voice-activated computer for word-processing and games. "Forty years ago, I couldn't call a nurse when I needed one," he remarks, "now I can communicate with people all over the world by fax, phone and the Internet.

A few years ago, when John entered the *Guinness Book of Records* as the longest survivor on a mechanical respirator, a neighbour's young daughter was asked why she thought John was so special. She replied, "He's the only man in

the world who can answer the front door by whistling."

They have no children through choice because John felt he would not be able to look after them properly. But now, not having children is one of his very few regrets. "If I started again, I'm sure I would have had a family, because we could have done." Polio does not affect the sensory nerves just the nerves that control voluntary muscles, so John and Maggie have a healthy, if modified, physical relationship.

John's life is always under threat. Even a common cold could kill him because he cannot cough. "I'm not keen on getting close to people with colds," he says. For us coughing may be an unpleasant inconvenience, but when the reflex fails, as it has in John, it can be catastrophic. If he contracts even a small infection the usual consequence is a lengthy stay in a hospital iron lung, coupled with frequent and painful physiotherapy and drugs to

overcome the infection.

He has 24-hour support from the medical and technical staff at London's St Thomas's hospital in London. A specialist unit provides all the necessary clinical and technological back-up that people like John need to stay alive and healthy. "With no back-up I could survive about three minutes if the respirator failed," he explains.

If a respirator breaks down, or the power fails, Maggie must be ready to take immediate action. This means that she can never be too far from John's side. They have standby respirators and electricity generators in case of such emergencies. When they go out shopping and John stays in the van, she can never leave him alone for more than a few minutes: "If I'm in a queue too long, I have to leave my shopping and check that he's all right."

Maggie says people thought she was sacrificing her life. Twenty-seven years

later, she proves them wrong: "I don't regret marrying John. We've grown very much closer, although people might think he depends a lot on me. I depend on him. I'd be lost without him. I'm his number one fan. I'd go through hell or high water for him." Such a statement would be powerful from either partner in any marriage, but is significantly more worthy in this one. "When I gained my freedom," John explains, "Maggie lost hers. I get all the sympathy and she gets all the work."

In 1994, John was awarded the MBE in the Queen's Birthday Honours List. He believes it should go to Maggie, for everything she does. "They said it was for service to disability," he says, "I think perhaps I'd touched people's lives. I'd been around so long, they probably thought they ought to give the old sod something."

Polio dramatically changed John's life, but he puts his own disability in perspective: "Many people look at me and



Polo provides much enjoyment for Maggie and John

think poor old John but it's not like that at all. People need people. Many people in this world aren't loved by anyone or anything. I'm very lucky." Of Maggie he says, "She's a very good woman.. She gives me the power to survive."

The hardest thing John finds about being disabled is

maintaining privacy. "You lose physical privacy, that doesn't worry me at all," he says. "The hardest thing to lose is emotional privacy. Most people, when they're upset, can go and hide in the loo but I'm on public display and, if you can't wipe away your own tears, you really feel your disability."

"There's nothing good about being disabled," says John, "but there are compen-

sations. I tend to see the better side of people's natures, and I've met people that I wouldn't have otherwise." Those people include many famous names, some of whom keep regular contact with John and Maggie, including HRH The Prince of Wales, whom they met in the late 1970s. At polo matches the Prince always makes a point of seeing them and as a young boy, Prince Harry was photo-

graphed attempting to push John's bed.

Yet John is frequently surprised at the impact he has made on other people's lives. In May 1985 he read an article in *Woman's Realm*. "We must continue to vaccinate our children against polio," wrote Dr Pat Last in her weekly health column; "When I was a medical student, I remember helping to nurse a very handsome young man

called John... he lived in a room by himself with a noisy iron lung." John recognised himself and wrote to Dr Last who had no idea, and little expectation, that John was still alive. "I am certain you are referring to me," wrote John, "though I'm not so sure about the handsome bit!"

John still has ambitions. Enjoying his first cordless picnic, mentioned earlier, John had an idea. "I liked it," he says, "I must do something about motorising this bed so I can drive myself around. In the 27 years we've lived in our house, I've gone to the end of the garden less than six times. It's such hard work. It would help Maggie and would enable me to do something I've never done in over 40 years, move from A to B without asking somebody."

And his second ambition? "When I left America in 1956, nobody thought that I would ever return, because no-one expected me to survive. But I have and I'd like to go back to prove it."