

Locked-In syndrome

One of the worst medical conditions must surely be Locked-In syndrome. It leaves you with all your mental abilities intact but totally paralysed, except perhaps for the blink of an eye. A perfect, working mind is locked inside a useless body: the sufferer can sense everything around but is unable to communicate with anyone. Despite this, one of the most uplifting books I have read is *The Diving Bell and the Butterfly*. It is the autobiography of Jean-Dominique Bauby, written after he woke up in a hospital bed with Locked-In syndrome. In the book, he describes a life with Locked-In syndrome, including how he communicated, not only with medical staff, friends and family, but also how he came to write the book without any technological help.

The book was written using a heroic form of face-to-face interaction. Put yourself in his position, waking up in a hospital bed. What would be the best way for you to write a whole book? You have only a helper with a pen and paper to write down your 'words'. The only movement you can make is to blink your left eyelid.

How did Bauby do it?

Bauby's helper read the alphabet aloud ('A, B, C...') When the letter he was thinking of was spoken, Bauby blinked. The helper would write that letter down and then start again, letter after letter. Try it with a friend – communicate your initials to them that way. Now imagine that that is the only way you can talk to anyone. I hope your name isn't Zebedee Zacharius Zog or Zara Zootle.

Bauby realised that the 'A,B,C' method could be improved upon. He had been the Editor-in-chief of the French women's magazine *Elle* before he became ill, so he knew about language. He knew that some letters are more common than others in natural language, so he got the helper to read out the letters in order of frequency in French, 'E...S...A...R...' That way the helper got to the common letters more quickly. A similar trick has been used through the ages to crack secret codes – (See the Beheading story on page 12) and for doing the crossword-like puzzles called cross-references (try one on page 18).

Now, as a computer scientist I immediately start to think that I could have made his life so much better (even without replacing the human helper with blink detection gadgets and the like). In the worst case, perhaps dictating a story where someone snores 'Zzzzz' would take 26 questions per letter.

On average, in the course of dictating the whole book, roughly 13 letters will be said per letter dictated. Bauby's modification improves things but the worst case is still 26. Thinking as a computer scientist, the problem is a search problem (searching for one letter in 26) and the solution he used is known as linear search. Other search algorithms are far better. From some simple computer science that I learnt as an undergraduate, I know that a search through 26 things only needs at most five true/false or blink/no blink questions – not 26.

Learning from a children's game

How do we do it? By using the same strategy as is used in the children's game of 20 questions. It is a search problem too – a search to find the name of a famous person out of thousands – and yet it does not take thousands of questions to win. Played well, you do not ask as the first question 'Is it Nelson Mandela?', the equivalent to 'Is it E?' Rather you first ask: 'Are they female?' and so rule out half the possibilities whatever the answer. The equivalent question for the alphabet is 'Is it before N?' Try it – start with 1 million and see how many times you have to halve it before you get down to one. 1,000,000 ... 500,000 ... 250 000...

A similar trick has been used through the ages to crack secret codes

Keep asking questions like that about letters rather than famous people and you get down to a single letter in no more than five questions. Tweak it based on letter frequencies and you can do even better for the common letters.

Bauby should have got the helper to ask such halving questions. Think about it. Five questions at worst rather than 26, multiplied up by all the letters in his book. If only he had known some computer science, how much easier his life would have been.

Now we have worked out a method we can think how we could automate it with suitable technology. How wonderfully computer science can improve lives.

But wait a minute. Perhaps the computer scientist would have ensured his book was

never completed and his life was even more a hell. Perhaps we should have started with the person rather than our bright ideas. What if blinking is a great effort for him? His solution involved him blinking only once per letter. Ours requires him to blink five times. Multiply *that* by a whole book. Furthermore, his solution is easy for anyone to walk in and understand. Ours is complex and might need some explaining before the visitor understands and Bauby is not going to be the one to do the explaining.

It worked for him!

One thing is certain about Bauby's solution – it worked for him. He wrote a whole book that way, after all. Perhaps the helper did more than just write down his words. Perhaps they opened the curtains, talked to him about the outside world or just provided some daily human warmth. Perhaps the whole point of writing the book was that it gave him an excuse to have a person there to 'talk' to all the time.

Replace the person and perhaps you have replaced the one thing that was actually keeping him alive. In an extreme 'usability situation' such as this, the important thing is that the user really is involved throughout the process. They are the ones who ultimately have to make it work for them, not only technically but also emotionally and socially. Otherwise we may devise a 'solution' that is in theory wonderful but in practice hell on earth for the user.

As you can see, computer scientists have to think about so much more than just computers.

Find out about Jean-Dominique Bauby and what life is like with Locked-In syndrome by reading: *The Diving Bell and the Butterfly* by J-D Bauby, Fourth Estate.

