

# FROM PROFESSIONAL TO PATIENT



Three scientists tell their personal stories of being diagnosed with chronic illnesses and how the transition from professional to patient has affected their work and lives.

## STEPHEN MORTLOCK

**Pathology Manager**, Nuffield Health, Guildford Hospital

I like to think that as an individual that I am pretty fit. I don't drink or smoke, I exercise regularly and exceed my daily quota of fruit and vegetables. Then, in the middle of last year, I started to notice that I was more breathless than normal, with an annoying cough which didn't get better.

It all became slightly more alarming when I woke up one morning with a rapid erratic heartbeat, extreme breathlessness, my legs felt like lead and I had a general overall feeling of something not being right. I decided a trip to the emergency department was in order. After being



poked, prodded and bled, I was sent off for a chest X-ray and transferred to the observation ward to wait for my results.

Later that day, the consultant came to tell me that my troponin levels and most of my other blood results were normal, but they had found an opalescence shadow down the right side of my heart, which would require further investigation. So the journey began.

## Diagnosis

I went back to the hospital the next day for a contrast CT scan using iodine dye. A couple of hours after the scan was completed, I was called into the consultant's office where he was waiting

with a Macmillan nurse, which seemed to herald bad news. Surprisingly, the revelation did not affect me as I thought it would have done. They had found a tumour in my right lung, not my heart. It was quite large (about 8-9 cm at the widest point) but it was a single tumour. Driving home from the hospital seemed to take forever and I had to break the news to my wife Caroline and the rest of my family and, of course, the team at work.

Now everything moved up a gear and the next few weeks were a flurry of further blood tests, investigations, different examination tables and sitting in waiting rooms reading week-old magazines. There was a lung function test, a PET scan and an MRI of my head to narrow down the options of the type of tumour that was growing in my chest. Appointments were made to see different consultants, as each new investigation

revealed something new. Finally, the last investigation was a CT-guided biopsy of the affected lung at the day surgery unit.

Eventually, we had a diagnosis. It was a stage 1E diffuse B-cell lymphoma (non-Hodgkin's lymphoma) in my right lung, with an associated build-up of pleural fluid. From initial diagnosis to the identification and then to my first cycle of chemotherapy was only five weeks. At every step, and for every investigation, I was included in the discussions and when discussing the available options. I must have asked thousands of questions.

## Treatment and effects

With a diagnosis made, the consultants could decide on the suitable therapy. Luckily, there was not to be any surgery, but six cycles of R-CHOP chemotherapy on a three-week cycle. R-CHOP is a combination therapy of rituximab,

doxorubicin, vincristine, cyclophosphamide and prednisolone. But the rituximab took four to five hours to infuse and the whole treatment effectively lasted all day. Then the treatment cycle was over until the next time. There were also the take-home medications, two days of ondansetron, four days of prednisolone and three weeks' worth of acyclovir and co-trimoxazole.

The first 48 hours after treatment seemed to be OK, but usually by the morning of the third day I was feeling lethargic, slightly nauseous and all my muscles ached. Then it got worse.

People have told me that you should be able to go to work in the periods between treatments, but there was no way that I would have been able to do anything constructive at work. However, on my better days



I was able to work from home and keep up to date with emails.

### Neutropenia

One of the problems I encountered was that after cycle two of the chemotherapy, my white blood cell count did not return to normal, so I had periods of neutropenia. As a result, over the course of the treatment, I had two separate chest infections treated with oral antibiotics and then I developed septicaemia, which was treated with IV tazobactam. To counter the neutropenia, I was prescribed filgrastim that they hoped would regulate the production of neutrophils within the bone marrow. This was a self-administered injection for me to take home after each chemotherapy cycle, five days of injections each time.

### Side effects

I lost what little remaining hair I had on my head, most of my body hair went and also my eyebrows, eyelashes and nasal hair. Then there was the tiredness, lethargy, muscle aches and cramps, nausea and, of course, the alternating bouts of constipation or diarrhoea, flatulence and haemorrhoids.

Then there was the evening I was injecting the filgrastim and that leg went into severe cramp. I had my tracksuit bottoms around my ankles, a hypodermic syringe sticking into my leg and was hopping around trying to relieve the cramp. It was both disturbing and comic.

Two days after my second cycle of chemotherapy, one of my teeth cracked, leaving me with a rough exposed hole. Since I couldn't visit my dentist we decided to get a temporary filling kit from the supermarket. I was lying on the sofa shining a torch in my mouth while my wife filled the tooth with putty.

On Christmas Day, rather than being with our families, we spent the day by ourselves with me alternating between shivering on the sofa and rushing to the toilet.

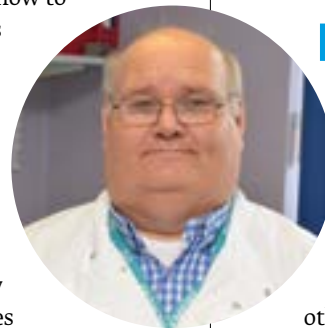
### The end in sight

My journey is not over yet, but the end is in sight. The lymphoma has shrunk from its original size to a few small non-viable cells residing in the lower part of my right lung. I will be under the care of the hospital for the next few years with regular blood tests, scans and reviews.

But now, having been on the receiving end of hospital investigations, it has highlighted the old adage that behind every sample is a patient, in this case it was me. I'm not the first person to have diffuse B-cell lymphoma and, I'm afraid, I won't be the last, but this journey has altered my perspective. I am always ready to pass on my experiences; to encourage newly diagnosed patients and tell them that although the treatment can be bad there is always hope.

I still have lingering after effects of the chemotherapy and radiotherapy but my body should continue returning to normal over the coming months. On the plus side, I don't feel sick all the time, I don't fall asleep while I'm eating breakfast and if I go for a walk I don't fall over my feet and my body temperature doesn't fall below 35°C. Also, I am now able to walk for more than five minutes without needing to sit down for a rest.

It is difficult to know how to thank everyone who has been involved in my diagnosis and recovery but certainly my thanks go to everyone at Frimley Park Hospital, from phlebotomy to pathology, but especially the chemotherapy nurses whose good humour made treatment day bearable and to the Macmillan nurses who were there to offer advice. A big thank you goes to the matron and the staff at Guildford Nuffield Health who continue to support me through my absences from work and follow-up appointments. But most of all



### NICK KIRK

Principal Information Analyst,  
Royal Papworth Hospital NHS  
Foundation Trust

After spending 31 years working in pathology and dealing with other people's diseases, it comes as a bit of a shock when you find yourself at the other end of the equation.

I have been a type 2 diabetic for over 20 years, and 18 months ago this led to total kidney failure. Within a week I went from being "normal" to being at death's door. An emergency admission to Peterborough City Hospital found me on the cardiac ward

*"I had needles and tubes galore stuck into me and was tested to oblivion and it made me appreciate what repeat testing means"*

my love and thanks go to my wife Caroline, my family and friends who were always there during my darkest hours when the outlook seemed very bleak.



with cardiac failure, connected to a bank of machines that go "ping" and an oxygen supply with a series of doctors looking over me with very concerned faces.

They managed to pull me back from the brink on two occasions, which then led to a three-week stay on the renal ward, where they tried to "dry" me out. In those three weeks they removed over 40 litres of fluid from me through a combination of diuretics and dialysis.

I had needles and tubes galore stuck into me and was tested to oblivion and it made me appreciate what repeat testing means to a chronically ill patient, something I may not have fully appreciated in the past. It also made me appreciate more the implications of rejecting samples and requesting a new blood sample.

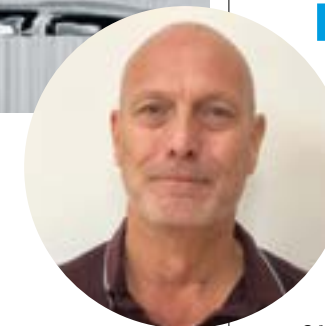
The constant testing became a real burden after a while and even though the phlebotomists were total professionals,

the sight of one at my side room door made my heart sink.

### The impact

Once I had recovered enough and had returned to "normal", I had an arterio-venous fistula constructed in my left wrist to allow easy access for haemodialysis. I now have dialysis three times a week after work, which has meant that my social life has taken a real knock. Fortunately I can flex my hours at work to accommodate the dialysis, which allows me to still work full time. It is tiring though.

My current condition now requires regular clinic attendance and Doppler scans of my AV fistula, all of which is time-consuming and has an impact on my job, as it has led to me having to use a number of annual leave days to cover these absences.



### HEDLEY GLENCROSS

Advanced Specialist Biomedical  
Scientist, Portsmouth Hospitals  
NHS Trust

### Mindset

Having kidney failure has turned my life upside down and my on-going treatment dominates my life. It restricts where I can go and for how long. Currently, the longest holiday I can take is two and a half days, which limits me to only going short distances away from the hospital. Fortunately for me, that includes the North Norfolk coast, one of my favourite places in the UK.

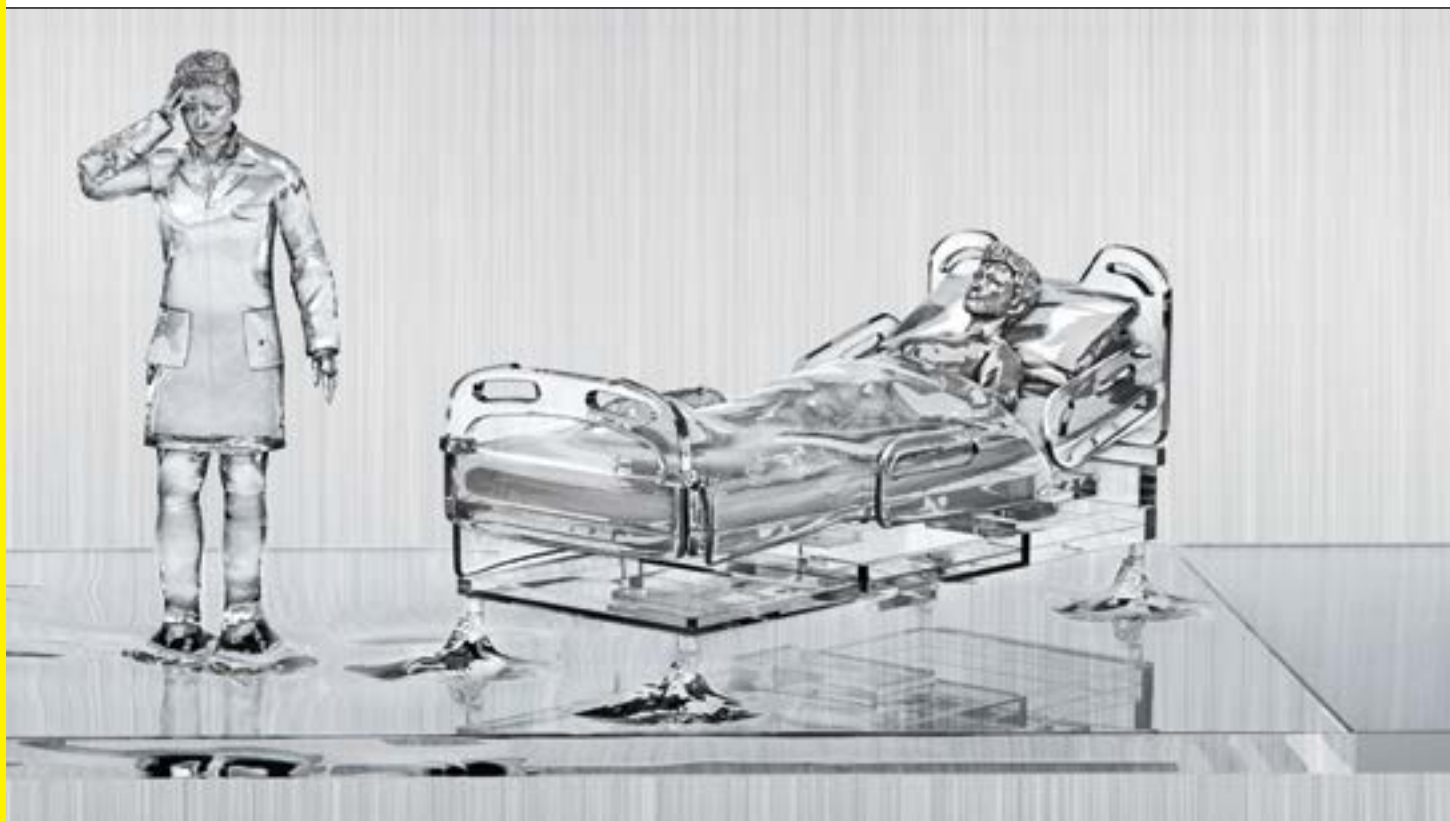
Most people think of themselves as indestructible and certainly coming from a pathology background, you perceive many of these diseases and conditions you deal with as things that happen to other people, not to you. When you find yourself in the position I have, you have to approach life with a totally different mind-set than before, which takes a lot of getting used to.

I was diagnosed with testicular cancer when I had recently turned 34, at the culmination of a number of stressful life events. I had recently moved house, having secured my first laboratory manager job, some 12 months previously after working away from home for over eight months.

It was very difficult as at the time of my diagnosis my son was just under two years old and among a large number of worries was the possibility that I would not see him grow up.

### Aware of issues

I've never told any of my family this, but I was aware of something being wrong for a few months prior to my definitive diagnosis. Even before I got my new job, I would arrive at home, pick up my



son for a “hello” and nod off to sleep almost immediately, I also suffered from regular short-lived colds, but of course this was just stress-related, wasn’t it?

Finally, I started to become uncomfortable and my right testis was feeling heavy, however; like men in general, I dismissed it thinking it would get better. But, being a good biomedical scientist and cytologist, I researched things and finally it was a single phrase in a cytology textbook that gave me the answer: “Painless hard lumps or alterations in size or weight of a testis are always suspicious”. This summed me up to a tee and prepared me for the worst news. Looking further, I fitted a classic presentation history.

Coincidentally, at that time, my son in his excitement jumped on me after a Sunday afternoon walk, creating some trauma in that area (ouch), which gave me an excuse to visit the doctor. Glad you did that Joe.

### Motivation

The upshot was removal of my testis, a CT scan that showed lung metastases and an ensuing gruelling six-month course of chemotherapy with all its wonderful side-effects, sickness,


hair loss and the like. Even when I was better, I had a blood test on my first day back at work, some two or three weeks after finishing chemotherapy and strongly against the wishes of my oncologist, and my Hb was 60g/L. Basically in its boots, but I felt wonderful.

Yes, you can get through major illness and come out the other side a more positive person. Being this ill was the spur to do other things and make something of my life, rather than just ambling along as perhaps I had done up to that point.

### Achievements

I can trace back to this event the reasons why I became an IBMS Council member, serving 10 years (and a further eight years as an IBMS employee), seeing projects I was involved in or initiatives I helped start, that are still part of the profession. It is also why I was lucky enough to get to work in Sweden with one of the arms of the Swedish Two-Counties Breast Screening Programme. Why I have edited and co-authored a book, why I have published papers, why I have taught and lectured widely. It is also why I remain active professionally as an executive committee member of BAC and why

I am involved with a UN-funded project to set up a cervical screening programme in Moldova.

Next year it will be 30 years since my diagnosis. Doesn’t time fly by... 

*Yes, you can  
get through  
major illness and  
come out the  
other side a more  
positive person*