

It has been an interesting (*sic*) experience observing Helen's treatment. As a director of public health and then medical director in various organisations in England before I retired, I was involved in many aspects of cancer care in terms of policy making and governance at different levels, and I would like to mention a few key issues relevant to this story here. I will be brief, and if interested you can see more about these and my views on the NHS, elsewhere on this website.

In 1998 soon after Sir Tony Blair became the Prime Minister, I joined a Working Group that was established to create the Cancer Strategy for England – it was to build on the work started by the two previous Chief Medical Officers who produced the Calman-Hine Report. This Working Group was an eye opener (and got me into Hansard!), especially since I had first-hand experience of national policy making and especially about Blair's ambitions – I had met him in the northeast where I lived and worked then. The NHS then adopted the strategy in England, and this has been guiding cancer care since, although the standards, especially around waiting times, have slipped.

So, in 2021, I was surprised to read that Wales did not have a comprehensive cancer strategy especially as Dame Deirdre Hine, the co-author of the Strategy, was a Chief Medical Officer for Wales in 1990. What does exist in Wales is a Cancer Delivery Plan and a Quality Statement. I am not in a position to say whether the absence of a strategy equates to the absence of good care though a well-executed strategy can surely help in achieving consistent good quality care.

I am, however, pleased to see the creation of the Citizen Voice Body for Health and Social Care in Wales (see Declaration). I am a strong supporter of this initiative to listen to patients having always felt that clinicians and managers should avoid doing things to patients and instead work with and engage them in their treatment. Patients do know a lot and we do not always acknowledge, respect or learn from this. Despite all the advances, getting a diagnosis of cancer is a shock; and though medicine can save and transform lives, the power of a positive mental attitude and a sense of ownership and agency for the patient can be a powerful tool in healing as well as a crucial aid in managing the day-to-day grind of treatment. I was also pleased to read that Maggie's Centre may be opening in North Wales, though not sure when; these centres are a good resource for patients.

The more challenging issue was to do with what I have described as the worst aspect of my jobs as medical director, and which was making decisions about funding for specific treatments for individual patients (Individual Funding Request-IFR). In brief, whilst the NHS provides a fairly comprehensive service, many times there are treatments which are not available as a matter of course and when the treating clinicians (and their organisations) have to seek permission to use them, and the accountability for this rested with me as the medical director of the commissioning bodies. Now with Helen's care the names of drugs like G-CSF, Taxol, Herceptin etc over the years flashed through my mind as I remembered when we discussed, as the team, what should be the policy of our organisation and what procedures we should put in place to review any requests for these. I cannot now remember how often these came up and what decisions were made, but I had always wondered how the patients and their families would have felt. It was not easy

being labelled as the 'Bad Guy' as at times we had to 'deny' the request for such treatments. The case of Late Tony Wilson in Manchester, who was 'denied' cancer drug for his renal cancer, is an example of the pressures I had to deal with as I got roundly criticised in local and national media. I used to feel dejected after every such episode, and more so as I used to constantly rail against the waste that I saw all round me in the NHS. The question that used to come up was: 'What if it was you/your child/partner/parent', but how could I (anyone) answer that?

To a small extent we faced this situation during Helen's treatment when she was not given the Long Acting G-CSF (a drug to reduce the side-effect of chemotherapy) which is better than the alternative that she was given initially since it is more costly. Helen however got it later after she was admitted to hospital with Febrile Neutropenia (a serious but well-known complication); so the small extra cost of the better drug ended up costing the NHS four days of hospital in-patient stay plus all the other drugs. Helen's chemotherapy doses had to be reduced too, with what effect on her prognosis remains a guess. Overall, Helen's life seemed like collateral damage and risk worth taking? There is no easy answer to such situations but serious conversations about the future of the NHS are long overdue.

Overall, I feel sad at the state of the NHS. We have been fortunate with Helen's treatment but many others including in our immediate circles have not been so for various ailments including breast cancer. Our own experience, when we were told that an ambulance was not likely to come for 3-5 hours when Helen had collapsed at the door after coming home from surgery, shows the challenges. We were in remote Peniel, and had our (elderly, sorry David) neighbour not sprinted up from his cottage down the valley or Helen not quickly recovered, we wonder what would have happened. It was also fortunate that I still have some medical knowledge and was physically strong enough to support Helen as she collapsed; a more elderly /infirm couple would have been very vulnerable in this situation.

I was also perturbed by the after-care – bleeding from the kind of procedure she had is not very common, and it was not treated seriously, with return visits to hospital, attempted aspirations of haematoma (?necessary) and transfusion. I have no idea whether this would have been treated as an 'incident' by the team, along with the Febrile Neutropenia she had. At least for learning and training purposes.

As an overseas doctor who 'chose' to work in the NHS I feel strongly about protecting and enhancing the Service; you can read about my experience of doing the 300 miles Jarrow March to protest against changes including privatisation and cuts, which have come to haunt us during the pandemic. The current NHS and social care is not fit for purpose, but there does not seem to be any political will to change; frankly the NHS has been stuck ideologically since Margaret Thatcher's reforms.

I feel that the Welsh Government has handled the pandemic better than the Westminster Government in England, but we have serious health and care issues in Wales, including in my local health board, and we urgently need some fundamental changes. I wonder if Wales has another Nye Bevan, the NHS would definitely benefit from some visionary leadership of his calibre now.

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