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NICE WORK IF YOU CAN GET IT: Life as a Children's Heart Surgeon

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Introduction

When I was appointed in 2014 to this post of Gresham Professor of Physic, I accepted a sentence of three years' hard labour. Those three years are up, and this lecture was to have been my swan-song. I thought it would be an opportunity to reflect on almost half a century as a doctor and more than thirty years as a children's heart surgeon. I hoped you would forgive this self-indulgence.

But it is not my swan-song. I have agreed to serve another year, and so this indulgence is merely an interlude before the more serious stuff of the next academic year.

The title of tonight's lecture is making its second appearance in my life. I used it for my inaugural lecture at University College London emphasising the academic side of my work and challenging some aspects of training.

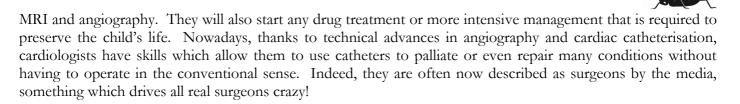
"Nice Work if You Can Get It". I believed it then, and I believe it now. For me, being able to do the work of a paediatric cardiac surgeon in the NHS has been the very definition of nice work; exciting, immersive, challenging, fun and above all a chance always to work with young people. Tonight, I hope to explain in a bit more detail why it has been a privilege, to speculate on whether it remains true for those entering the profession in England, and to consider what the future for them might look like. I'll start by describing briefly what a children's heart surgeon does, and how the system works.

The Role

A paediatric cardiac surgeon's job is to repair congenital (present at birth but not necessarily hereditary) heart defects. Essentially a plumber who repairs biological pumps. The heart is a complex structure, and the number of congenital abnormalities which can exist is large; over 3500 individual items. There are more than 2000 individual procedures which make up the surgeon's repertoire. It is a job that cannot be done alone. The surgeon is but one cog in a large highly integrated machine devoted to improving the lives of these children. The work is the epitome of teamwork.

These days, during pregnancy, a woman will usually have several screening ultrasound examinations to ensure her baby is developing normally. If the sonographer is worried about the baby's heart, a more detailed scan will be performed by a specialist cardiac sonographer and if anything is wrong the family will be seen by a fetal cardiologist, working in one of the recognised cardiac units around the country. The diagnosis and treatment options will be discussed, and if major surgery is going to be needed after birth to correct the problem, a surgeon like me may be brought into the discussion to help the family decide whether to proceed with the pregnancy or how aggressive treatment should be after birth.

After the child is born, or if the diagnosis has not been made during pregnancy, the child will be seen by a paediatric cardiologist, locally or at a specialist centre. The cardiologist is a physician, whose role has traditionally been to establish the diagnosis using clinical assessment and imaging tools such as ultrasound, CT,



Occasionally, and more often in the past, it is necessary for the cardiologist to ask the surgeon to operate immediately, with the decision being made by them in conjunction with the family. More often, each new patient is discussed by a much wider team in a multi-disciplinary team meeting (MDT) to review the evidence for the diagnosis, to consider available options and to agree a plan to discuss with the family. This MDT is the heart of a specialised cardiac unit. A visible expression of the importance of teamwork and the dedication of the whole team to providing the best for an individual child and its family. A common public perception is that the individual cardiologist and surgeon are the sole decision makers. When the BBC presented our MDT meeting in a documentary a couple of years ago, it became clear that most viewers had little or no idea how much time and energy is devoted by the team to considering the options for an *individual* child. In fact, each child having surgery is discussed at least twice in such a group with the second meeting being a cross check of the first to make sure we are doing the right thing; internal peer review and quality assurance.

It is, of course, the surgeon who carries out the heart surgery, again with a huge team of nurses, perfusionists, anaesthetists, technicians, porters and junior surgeons in training. After surgery, care is delivered by intensive care specialists, supported by surgeons and cardiologists, and follow up is done by the cardiologists as close to the patient's home as possible. There are regular review MDTs for those patients who need on-going care, all with the focus on providing the best quality of life.

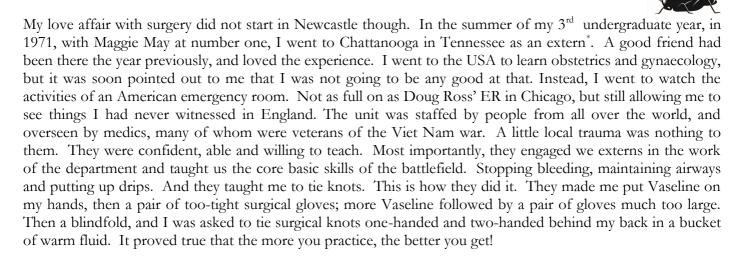
The surgeon is often perceived, especially by the press, as being the leader, but in truth one is just a critical member of a team, lucky enough to possess the practical skills to be able to operate. The surgeon is generally perceived as the one 'who carries the can', and one often hears questions like 'who's your surgeon?' and 'who's your cardiologist?' The team is hidden and the care personified and long term relationships established

It has been very 'Nice Work', not least because of its setting. I have worked all my life in the much bigger team of the NHS, in my view one of society's greatest developments. Children have no control over their health, especially for those things they are born with, and young families are often at a stage in their life when their income is stretched. I am proud that I have worked in a system in which care is free at the point of delivery. I am also proud that such care has been delivered to the highest international standards, and that we have been able to innovate, improve and excel. I have been surrounded by dedicated people who have given energy, time, focus, empathy, love and support to families at their lowest ebb. They have all gone the extra mile. They work for the children and not for the money.

Getting There: Undergraduate

I went to medical school in Newcastle-upon-Tyne. I was just 17, having saved a year at school. Too young, legally, to drink in a pub. Not too young though to dissect human cadavers, which I found myself doing within 2 weeks of starting University. It was terrifying, shocking, and simultaneously exhilarating. A bond formed with my five fellow students at the table, and with the generous person who had donated their body for us to learn. I loved the practicality and precision of the dissections, and still think this is a marvellous way to teach the intricacies of the human body. Many students nowadays must learn anatomy using MRI images and other electronic images. Some don't learn formal anatomy at all. As a surgeon, I have found touch is part of my memory, and I worry that new students will miss that haptic feedback.

I was lucky to go to Newcastle when I did. It's teaching was outstanding, and engaged us with patients from day one Creating a relationship between basic science and individual people and their problems was a great way to lock important concepts in the memory. The face of the patient always came back to me; personalising care and humanising science.



Shortly afterwards some 'rioting' broke out in the streets, and I was needed as the ER put all hands-on deck. I had to deal with a bleeding artery deep in someone's pelvis, and now had the skills to do exactly that. It was both terrifying and satisfying. And made me realise that, as a surgeon, I really could make a difference to a life. Immediately, and with my own hands. I might even be able to **save** a life. Surgery became a career choice and not just an interest. I knew I wanted to do something **practical** with a relatively immediate return, and surgery offered that chance. A privilege.

Postgraduate

There was a recognised training path in those days. First, you applied for what were called House Jobs, like an American intern, and preferably in the main teaching hospital. Then one had to do a Senior House Officer (SHO) post before training as a General Surgeon on a rotation scheme and passing the FRCS before specialising. To become a paediatric cardiac surgeon, you had first to qualify as an adult cardiac surgeon. It was going to be a long haul.

I was lucky enough to work as a Houseman on both medical and surgical professorial units at the Royal Victoria Infirmary in Newcastle, and had a wonderful year working obscenely hard; no shifts to start with, long weekends and sick patients. Our relationships with our colleagues was critical and we helped each other and covered each other. We had responsibility for all the patients on our traditional Nightingale wards, and were expected to know all about them, all the time. On call periods were 36 hours at least and weekends started on Friday morning and finished on Monday evening. There was, however, continuity of care. Handovers were few and quite simple. All that has changed.

It was also like a family. We were fed and watered in the doctors' mess, accommodation was provided, and although basic created a community spirit. There was a bar, and we often met our patients there and learnt about them and their lives. We were learning about medicine and responsibility at a dramatic rate. We were mostly single, mostly men and some were a little wild. Parties were good, and there were the traditional junior doctors' japes; things that would have got us sacked these days. They would make another lecture on their own.

Consultants were Gods, to be feared. Your career was in their hands and teaching was quite often by humiliation. Ward rounds were very like Doctor in the House, led by a Lancelot Spratt in a white coat and trailed by acolytes of diminishing rank. The source of discipline was the Ward Sister, truly "She Who Must Be Obeyed". It was always a she.

I was training to be a surgeon, and naively held the view that I would be operating. Sadly, I was not often in theatre. Most of my job was talking to patients, examining them, ordering tests, taking blood and writing everything up in the notes. I have very strong memories of filling in endless blood test forms during the night and taking blood from the patients before anyone else arrived. I had to chase up the results and know them if asked. There were no computers.

^{*} An overseas student doing the job of an intern, but under supervision. There was usually a small stipend



The rare trips to the operating theatre were real treats. Sometimes I even got to hold a retractor, although retracting the liver so that a surgeon could see the gall bladder meant that I could not see and, having been up all night I often found myself falling asleep. I know I can sleep standing up. In fact, some years later, when my wife was in labour with our first child, I was in the operating theatre assisting with the theatre sister Babette communicating with my wife regularly asking her if she could just hold on a little longer. I wasn't released to go the delivery ward (in another hospital) until the very last minute. I was so tired when I did get there that I fell asleep standing up and the obstetrician was left to mop my wife's fevered brow.

The house year flew by in a haze, and we soon found ourselves fully registered doctors, let loose on an unsuspecting world. In fact, of course, it was just a license to do even more work and study for even more exams, in my case the Fellowship of the Royal College of Surgeons. The first part was more basic science, and the best way to have time to study was to teach Anatomy, which I was lucky enough to do for a year, ending in passing my 1st Part FRCS.

I had been in Newcastle for 7 years by now, and felt it was time for a change. So, I applied for a job as Senior House Officer in surgery in Southampton and Lymington in the New Forest. It was a great eye opener for me; a truly different life from the North. The weather was warm, the people friendly, the New Forest wonderful and the sea close by. What was not to like? Except that the population increased massively as the tourists flocked to the New Forest.

It was, however, scary. My first real exposure to surgery. And a demonstration of how things have changed over the years. Just before my first weekend on call, my boss, an elegant and distinguished ex-naval man asked me if I would like to go sailing with him at the weekend. Sadly, I was on call and had to refuse, hoping he would take me on another occasion. I took the opportunity to ask him what I should do if any problems occurred over the weekend (he was on call too). He answered, with a slight smile, "If you need me, I'll be in Cherbourg". He was sailing there; of course, without a mobile phone. I did have to operate that weekend, with the help of a brilliant experienced theatre nurse, and a good textbook on a music stand. I was very glad I had done so much anatomy. They were **very** different times.

I am glad that teaching is not like that anymore, but it did instil a form of confidence, and set me up for a great operative experience in Southampton itself, where my training was carefully calibrated and extended until I was ready to apply for a proper surgical training rotation, a prerequisite to being allowed to take the Final FRCS examination. These registrar rotations happened all over the country and were quite competitive. Newcastle interviewed first (probably because it was so cold) and I was accepted and found myself, once again, working on the Professorial Unit as a junior registrar in Surgery.

The good thing about rotations is that you get to have a taster in several specialities. I did General Surgery, A&E, Cardiothoracic Surgery and Plastics. I did not get on with general surgery, which I found rather dull. And certainly, it was much more smelly than heart surgery and plastics. I really enjoyed both these 6 month tasters, and was especially motivated by a plastic surgeon who was one of the most humane gentlemen I have ever worked with; David Crockford. My thoughts at that time were that I would end up doing plastics....I loved the hand surgery and the ICU care of burns victims was really challenging.

But a phone call from the cardiothoracic surgeons I had left 6 months earlier changed all that. They wanted to know if I would consider a fellowship in San Francisco for a year. It seemed attractive, with the only fly in the ointment was that I would have to spend another few months in cardiothoracic surgery so that I would not let the side down if I went to the US. I went back to cardiac surgery, and never left.

Cardiac surgery was just over 25 years old. Systems had improved, but it remained very hard work. Operations were long, bleeding common and intensive care difficult; managed at the bedside by junior surgeons like me, supported by anaesthetists. After a full day operating, we would often be up all night managing some crisis or other and then operating again all the next day. It was, however, a wonderful mix of the practical skill of surgery and the intellectual challenge of manipulating the physiology of a patient with fluids and drugs. Untoward events happened, and it was necessary to react immediately and correctly if the patient was not to suffer. The sense of responsibility was profound and one really felt one was doing something useful, and immediate.

There were occasions when you really could say you had saved a life. And, sadly, others when you failed. It was emotionally and physically draining. It was all-enveloping work; work which just kept coming. And, like all my peers, I was also having to study for my Final FRCS in any gaps I found. In retrospect, it is really hard to imagine how it was physically possible, and how stressful it must have been for my wife.

During that time, I met George (now Sir George) Alberti who was the young professor of clinical biochemistry in Newcastle. He went on to become, amongst many other things, President of the Royal College of Physicians. Biochemistry was not one of my natural talents; indeed, I had managed to get a massive 3% in one biochemistry exam as a student, probably for correctly spelling my name. George was very scathing about surgeons. He was pretty sure that our brains were smaller than normal and that our hairy-palmed hands trailed on the floor. Any kind of intelligent comment must be purely a random event.

One evening, he asked me why I was doing something like cardiac surgery when there were **real** problems to solve like diabetes. At the time, there was a very high death rate amongst diabetics having cardiac surgery. George Alberti suggested that something should be done about this, and persuaded me that we could sort it out by researching both the metabolic effects of cardiac surgery and identifying a more precise way to manage patients with diabetes during and after surgery. We pencilled out a research project and with the help of Mike Holden, my surgical mentor at the Freeman Hospital, Newcastle, tidied it up and applied for a grant from the British Heart Foundation.

Much to my surprise, we got the grant. My contract was short, and the team negotiated with the NHS and the University to make me something called a First Assistant which was a sort of academic senior registrar post which allowed me to do clinical and academic work simultaneously, shortcutting the route to a Doctorate. As mad an idea as it was exciting. The workload was ridiculous, on call alternate nights and up doing science the other. The work involved attaching patients to an artificial pancreas which measured blood glucose and infused insulin according to algorithms which we could manipulate. Blood samples had to be taken pretty well hourly. This was the early 1980s. Computers were massive and had to be re-programmed regularly. Data management was manual, and we had to use Letraset to make graphs and tables and photograph typed sheets to make slides. What is now easy and rapid on a laptop was hard and very slow in those days.

But it worked. We modified the way in which both cardiopulmonary bypass was carried out and improved the control of diabetes during and after surgery. The techniques we described remain in use. And I did get my Doctorate.

The experience taught me many lessons. I learnt that research is critical to improvement, and that good data are needed to convince sceptics of one's findings. I learnt that research is hard, and researchers under-valued and usually under-paid. I learnt that there is much to be gained from making links *outside* one's own clinical silo and that there is nearly always someone nearby who knows more about some aspect of what you are doing than you do. And I learnt that they usually like being asked for advice.

I never did go to San Francisco. Sad, I suppose, but I think the research experience I had in Newcastle has been better for my career in the end. The team there were supportive in every way. And by doing the academic and clinical jobs simultaneously, I accumulated a massive amount of surgical and intensive care experience in a relatively short time.

Towards the end of my training, when the dominant adult cardiac operation had become coronary artery bypass grafting (CABG, pronounced cabbage), something happened to me which changed the course of my life. I was doing a CABG, attaching a saphenous vein to a calcified coronary artery, when I found myself looking at the clock, to see how long it was taking me. The competitive currency between surgeons at the time was 'how long does he take to do a distal end'. I had forgotten about the poor man on the table; he had been reduced to a technical exercise.

I realised that that was not for me and that I wanted more from my medical career. And the number of operations you had to master as an adult cardiac surgeon was relatively small. Something had to change.



Fortunately, I was working with a surgeon with a mixed adult and paediatric practice. His name was Mike Holden. He was wonderful to work with; passionate, committed, caring and gentle. His sense of responsibility for the lives of the children he operated on was extraordinary, and he struggled with that sometimes. But he showed me how to care and embedded that core value in me. He also had what surgeons call a wonderful pair of hands, and was a delight to assist.

He introduced me to the mysterious world of congenital heart disease, which required me to relearn everything I thought I knew about the heart to begin to understand the complex interrelationship between abnormal form and function, and how one might bring it back as close as possible to normal. Congenital heart abnormalities are difficult enough to understand in these days of MRI imaging, 3D reconstruction and virtual reality. In those days, it was much harder. You had to use your brain to reconstruct an *internal* 3D model of the heart from 2D noisy echocardiographic images and angiography. The stethoscope was still integral to diagnosis and the skill of the cardiologist in collating all the relevant clues was impressive.

Humility

The individual conditions we treat are relatively rare, and so to gain sufficient experience to be able to deal with anything that comes your way, requires you to work in a large centre seeing many patients. Newcastle was a relatively small unit, and it was suggested that I apply for a year's fellowship at Great Ormond Street (GOSH), the biggest unit in the country, to learn more. A consultant job in Newcastle seemed a likely outcome and so I went to London with plans to return north.

GOSH had long been famous for the close working relationship between surgeons and cardiologists. As I explained earlier, decisions about patient care were (and indeed still are) made at a multi-disciplinary meeting called, at GOSH, the Joint Cardiac Conference or JCC. I still remember my first JCC. A packed room in a Portakabin on a cold January day. A room full of people known to me only from the medical literature or their books, with additional famous international visitors and a palpable air of confident expertise. Hardly anyone was English. I was terrified, and my feeling of insecurity was not helped by the fact that I didn't understand *anything* about the disorders of the first three patients presented. I was desperate not to be asked a question. There were two other fellows (senior registrar equivalents) that year; one was American, Tom Karl) and the other a Canadian called David Wensley. They seemed to understand everything, which left me even more nervous.

However well I thought I had done to get the fellowship at GOSH, I soon realised that I was just at the beginning. I had to reset my mind to that of a naïve student again and observe, participate, learn and read as much as I could. The brilliant minds I encountered on that January day in the JCC proved more than willing to explain, to challenge and to help. Tom, David and I supported each other and exchanged learning, usually in The Lamb or The Queen's Larder, or by the bedside in the room that passed for an ICU.

It was also a shock to realise that all the nurses and most of the patients appeared to know more than I did. Happily, there was little, if any, intellectual snobbishness. Everyone realised there were many things that *they* did not know and it was generally agreed that there was no such thing as a stupid question. They had all found the intricacies of congenital heart disease difficult to grasp at first and had understood the subject at different speeds and in different ways. These were important lessons and I have found this to be a common feature of all the best units. You learn every day, from everyone. Another privilege.

At the end of my first year as an SR at GOSH, I failed to get a consultant job in Newcastle. Advertised as an academic paediatric job, it went to an adult cardiac transplant surgeon. Suddenly I had no future. My time at GOSH was running out, and no UK consultant paediatric surgical posts were anticipated in the foreseeable decade. I was deeply upset and there were tears. Very depressed, I came back to GOSH where the consultants kindly gave me an extension to my post. During the coming months, the two surgeons decided with the hospital to advertise for a third. Light at the end of the tunnel, I thought; until I saw the list of international applicants. However, I was very lucky and was given the job joining the consultant team at GOSH in 1985.



The Children and Their Families

It is not a job for those who don't like children. But to be able to work with them is the greatest privilege, despite what actors say. I have loved working with children and their families. Parents seem to fight harder for their children than they do for themselves, expecting more information, clearer descriptions of possible outcomes and detailed descriptions of the operation. Children themselves are, from a very young age, able to understand a great deal more than they are often given credit for, and finding ways of explaining complex problems to a child is very good for a surgeon. It prepares you for presenting the information to others. If a child can understand it, so can another surgeon, a finance director or an ethical committee. These days, many older children will have watched an operation just like theirs on YouTube. Indeed, in a clinic, one of my patients was watching the operation he was due to undergo (found on the Internet) on his iPad whilst I was talking to his parents.

We record most of our operations as video files, and following requests for relatives have shared these with both family and child. We were uncertain whether this was a good idea or not, but found that it was often very welcomed¹. Children used it to explain what had happened to their friends, in show-and-tell sessions at school, sometimes with our help. And parents described the recordings as replacing lost time whilst their child was away from them and they were unsure of whether they would see the child again.

Children and young people learn quickly and are usually not afraid to ask searching questions. It has been my experience that, on the whole, the more you share with them the less nervous they are. Even if the treatment you propose is difficult or innovative. You have to tell people facts, be honest about the risks, and give them time to reflect before signing anything.

Building that relationship does come at a cost though, at least for some surgeons. For those of you who saw a previous Gresham lecture (https://www.gresham.ac.uk/lectures-and-events/the-size-of-a-walnut-your-heart-in-their-hands) you will have seen some of my international colleagues explain that they prefer NOT to know too much about the child before surgery. It makes them too emotionally entangled and they feel that it affects their technical performance. I respect that; after all we are there to operate and do a great job. Most of us would I think settle for a brilliant surgical result from a distant or grumpy surgeon, rather than have a friendly surgeon and a poor result.

Occasionally you see the place in which you work in a new light. Victoria Derbyshire once did her radio show from GOSH, and I had the interesting job of accompanying her around the hospital as she interviewed children and their parents. In the way of an experienced journalist, she asked those children old enough why they were in hospital. Both of us were astonished at the depth of knowledge the children had about their conditions, and by the fluency with which they explained it. I have had medical students who couldn't do that! I was very proud that our staff had clearly not only told the children about their conditions, but also helped them *comprehend* the problems and choices they faced **and** be able to explain them. Never underestimate children.

As a surgeon, you share a great deal with your patients and their families. They are going through some of their hardest times, and they need to have confidence and trust in you and the team and be assured that you will be there when they need you to do the right thing. Mostly though, and because surgeons work largely in the operating room, contact with the families over time is maintained by paediatric cardiologists who see the patients in clinics, often nearer to their home town. Their relationship with families and children is much closer, longer term and critical to the good quality care. Because cardiologists are so close to their patients, and see the consequences of surgical repair, they have to have trust in their surgical colleagues which they in turn must pass on to their patients. This is a heavy responsibility.

Cardiologists, surgeons, nurses and play therapists spend a great deal of time preparing a child and its family for surgery. We explain the risks, benefits and the likelihood of success. Risk is difficult to perceive and hard to explain. A 5% risk of dying during or after an operation can be explained as a 95% success rate, 19/20 do well or as 1:20 will die. You must try and find the right way for each family, but must always be honest...and accurate. People often almost shut their minds to the risks, but they cannot give informed consent unless they do understand. It is our job to do that, and it may take many conversations and considerable time to do well. We each find metaphors which help. In my case, a graphic description of a 5% risk of crossing a road has often



helped. If you line up 20 children to cross a road, knowing there is a 5% risk, then one of the 20 is not going to make it to the other side. One naturally assumes one's own child is amongst the other 19. If, however, you are lined up amongst another 20 children behind the first cohort and are then invited to cross the road at the same level of risk, it is much harder to feel optimistic if you have seen that one of the previous 20 did not survive. We must also remember that when parents hand their child over to the anaesthetist at the start of the operation, they do not know they will get the child back at the end of the procedure, even if the risk is only 1%. For them it is binary and **feels** like 50:50 irrespective of the numbers. The people supporting them whilst their child is away need to understand this.

Stressful though it is to impart the concept of risk, as well as being the person physically delivering that risk, few things are as rewarding as giving good news to a family after an operation has gone well. The relief on their faces when you tell them all has gone well is wonderful to behold. It is impossible to underestimate the positive effect that handshakes, hugs and kisses from a relieved family have on you. It is highly motivating. And necessary to balance the bad times.

I have frequently found myself *fighting* for individual patients. There are times when, for some reason, you feel the fate of a child really does rest in your own hands. Times when you know your own commitment and energy will be required to motivate others when they are tired and beginning to flag. Times when ideas are short and solutions seem remote. Times when you just feel you must attempt something unusual, untried or heroic in the hope you can get the child through. I have been privileged to have experienced such emotions several times in my career, and lucky enough to work in a team and institution where the child comes 'first and always', and where innovation and creativity are fostered. Lucky enough too to have been associated with new interventions which worked out well and proved reproducible.

Of course, decisions to try something new are rarely taken individually, and are almost always based on a solid framework of experience, knowledge of the work of others and within a strong ethical framework. We never want to make the life of a family or child worse by our actions and our first duty is to do no harm. But, in partnership with the family, we are willing to try, and provide some hope for the future. This is called compassionate care; when we are allowed to try something for one patient before the evidence base is complete. There is a phase before proof of a treatment's success or otherwise exists when care must be individualised. Such events are relatively rare, but the experience gained in these cases can move the science along quite quickly and stimulate new research questions in the hope of defining the optimum treatment. The fight for a single patient has often led to victory in the battle for the lives of many. Sadly, sometimes that individual fight is lost, and one understands each medical advance is not built solely on the shoulders of previous scientists, but rather on the shoulders of the children and families who willingly took part in an experiment not only to see if something might work for them and but also for the potential benefit of others.

Very little can prepare you for sharing bad news with parents. No matter how many deaths or poor outcomes one has had to deal with, each time is unique, and uniquely stressful. As the surgeon, the person wielding the knife, and whose name is (metaphorically) on the end of the bed, you always **feel** accountable even if the cause of the bad outcome was nothing to do with anything you did. The job of informing the family often falls to the surgeon. Sometimes people just see it in your eyes or body language, and speech is superfluous or even invasive. On other occasions, you might be beaten about the chest by a distraught relative as the bearer of bad news, the focus of their distress. More often, we have a little time to prepare the family for the inevitable and indeed to share at least some of the experience with them. Nothing can compare to what the family goes through, but because we were so closely involved with child and family it is intensely emotional. By its nature, it is often the last task of a long day, it can be hard to pick yourself up and behave 'normally'. Few children die after cardiac surgery these days, but it remains difficult to re-enter your own home life after hours of emotionally draining trauma with a family. And difficult too to 'climb back on the horse' and operate the next day.

And of course, the work must carry on. Other patients are ill and need our attention. Surgery still takes place every day, and emergencies keep coming as new babies are born with congenital heart disease. Fortunately, over 80% of them get better quickly and never need to see us again. Indeed, they are usually glad not to, as they associate us with the stress and pain of it all. This perhaps explains why some surgeons prefer to keep it technical; the relationship may not be as necessary as one first thought. Nonetheless, I am sure that resilience is a necessary characteristic of a children's heart surgeon.



Changing Times

It was 1984 when I went to GOSH, and much has changed since. New operations have been developed, the heart lung machines have improved hugely and post-operative care is radically different. In those days, patients were taken from the operating theatre to an area which was not an ICU as you know it today from Holby City. It was actually a 3-bedded side ward off a corridor in a narrow 1930's building which still exists. The nurse who ran this area was Adelaide Tunstill. She was (and is) a formidable intelligence, who understood congenital heart disease backwards, and taught all of us who passed through that unit a massive amount. She was firm and authoritative, clear and concise, and in the most effective way, did not take any prisoners. We had to exceed her standards, which were based on the needs of the patient, a commitment to excellence and a devotion to her wider team. It was a great lesson in leadership for which I will forever be grateful.

There was little space, monitoring of pressures inside the blood vessels and chambers of the heart was by columns of fluid rather than electronic transducers. The range of available drugs was more limited than today, ventilators were less sophisticated, and mechanical support for a failing heart was not available. Records were kept on paper, all infusions were calculated and made up at the bedside and these were delivered not by the astonishingly accurate syringe pumps we have today, but by drip sets with roller clamps which meant you had to count the drops of fluid per minute to assess the accuracy of infusion rates. We junior surgeons were responsible for the patients at the coal face, relying heavily on the experience of an amazing team of nurses. As I implied earlier, ICU as a discipline was just beginning and our immediate supervision gradually shifted from senior surgeons to cardiac anaesthetists with an interest in ICU. This proved to be a really effective mix of skills and rapid progress was made.

We were often up all night. And then operating the next day. It seemed relentless, but was never dull and was the start of something for which I have been very glad. I rarely saw the exact same thing twice in my working career. Each child and each day were different. It was always new.

In the early 1980s, surgery was still often needed at night, and in a hurry. Many congenital heart conditions associated with obstruction of blood flow in either the aorta or the pulmonary trunk required the child to have a patent ductus arteriosus (arterial duct) to survive, shunting blood from left to right or right to left sides of the circulation depending on the specific morphology. If the duct began to close as it naturally does after birth, then symptoms rapidly became severe, and we had to operate to palliate or repair the child. Often at night, and with the child often in a precarious state; pre-term, tiny, acidotic and blue. The whole team would come in as quickly as possible and we young SRs would get started to minimise risk. Gradually we did more and more cases and were able to manage these emergencies independently. It was an eye-opener to see the dedication, stamina and commitment of all the team, especially the consultants who were in night after night; not only operating but teaching us, and giving us confidence. Everyone was devoting their energy to save these children and give them as good a life as possible.

A drug called Prostaglandin E1³ changed our working lives. This drug could be infused into babies and had the effect of keeping the arterial duct open. Gradually through the 1980s experience with PGE1 increased and rules developed. It became possible to stabilise babies on PGE1 and allow their clinical state to improve before we operated. Mortality and complications fell quickly, and that together with important advances in anaesthesia, CPB and surgery itself heralded a move to major reparative surgery on bypass in neonates. It was a sea change. We surgeons got more sleep, whilst the cardiologists and the soon-to-be intensivists took more of the out ofhours flak. But the operations we did during the day became more complex and were performed on younger and smaller babies.

The intensity of work meant that we became close to families and children and began to understand more about the impact of both disorder and treatment on their lives. We were always around, and they talked to us. It is difficult in the abstract to imagine how terrible it must be for a family to discover that their child has something serious that may need multiple surgeries, long term medications and regular review, often in a place away from your home and friends. We were given privileged access to the experiences of such families. Being able to listen to them and gradually to understand more of what their various lives were like has been a core part of why I do what I do, and why I feel so strongly that providing the best health care we can should be part of the definition of a civilised society.



Workload

Earlier I mentioned my time as a senior registrar at GOSH with David Wensley and Tom Karl. Having David there turned out to be both a blessing and a curse. David is an intensive care specialist, but at the time there were hardly any such people. ICUs were managed by anaesthetists and surgeons, in parallel to their day job. He had come to London to learn more about how to care for cardiac patients after surgery, but he did not want to operate. This meant that Tom and I operated almost every day, proportionately increasing our experience with the two renowned consultant surgeons Marc de Leval (from Belgium) and Jaroslav (Jarda) Stark from Prague. That was the good part. The bad part was that Tom and I had to cover all the out-of-hours surgical work on a 1:2 rota, as well as managing the post-op patients on our nights on call. We also had to be second on call 1:3 with David if something really big came up and more hands were needed on deck.

Marc and Jarda made it possible for me to continue the research work that I had started in Newcastle, and that had to be fitted in as well. It was killing, especially as my young family had stayed in Newcastle whilst I completed my training, since the assumption was that I would go back to Newcastle. My trips home were short and too infrequent. At best, it was every third weekend. My two-year-old son was convinced that I lived at Central Station in Newcastle. Even when the family eventually moved to London, quite often I was only home 2 nights in seven. It was immersion therapy!

The working life of a senior registrar in cardiac surgery in those days was intense, and perhaps worth describing. Daily work began early. We were very senior (now 12 years post graduate) compulsorily resident on site, and one of the three of us would have been by the bedside of the sickest patients most of the night. The two consultants were both (very) early birds, and obsessional about their patients. One used to go swimming at just after 5 am, and went to GOSH after that to see how his patients were. The other would have been phoning through to the nurses on ICU and the SR on call for a morning briefing on his patients. We all met for a joint ward round with cardiologists, anaesthetists and nurses at 0730, and woe betide the SR if you didn't know all the relevant details of what had been happening to the patients overnight and didn't have an outline plan for the day. The consultants already knew, so this was a daily test for which we had to prepare by being there even earlier and preparing perfectly.

The people on the ward round were, as I implied, world authorities. They had written or were writing 'the book'. Discussion was informed, intelligent, searching and hugely educational. These were people at the top of their game, in a young and still developing discipline in which new techniques of diagnosis, medication and surgical repair were being worked out rapidly, largely by them. As the SR, you were very exposed, usually the prime focus of questioning, and there was no shade in which you could hide. But there is something invigorating about being put on the spot by some of the best people; it can lift you from the deepest exhaustion. After the ward round, we went to the operating room, and we were expected to have ensured that everything was ready and prepared, and that we were completely *au fait* with everything to do with the patient. History, diagnosis, imaging, blood test results and relevant family details. We had already discussed all this with the perfusionists, theatre nurses and, of course, the anaesthetists, themselves internationally renowned, highly skilled and very quick so surgery usually started promptly. It was our job to begin the operation and get it to a stage where the consultant could move rapidly on to the core of the procedure. As we progressed through our training, we did more and more of the procedure, supervised until we had demonstrated that we could perform technically, tactically and effectively within the team.

Surgery was long, heart lung bypass more primitive, equipment less sophisticated and, for example, postoperative bleeding was more common. As SRs, it was our job to be there throughout the operation, from opening to closing, and take primary responsibility for ensuring that any bleeding had stopped. This often took hours. If bleeding recurred, it was our job to return the child to the operating room to fix it. These were hard hours if you had been up all the previous night, or were expecting to be with the patient all the coming night; both frequent events.

Accountability

However well you think you are prepared for life as a consultant, there is one thing that still comes as a shock. The realisation that the buck really does stop with you. You are suddenly expected to solve all the problems thrown at you and are conscious that in the MDTs you are expected to both have and express a view, and often



to make the final decision. Everyone is watching you to see how you stand up to the strain. I vividly remember, not long after I was appointed, when I had just finished pontificating about the plan I proposed for a patient, a strong New Zealand voice piped up from the back "I've never heard such a load of bloody rubbish in all my life!". It may even have been ruder than that. The voice belonged to Sir Brian Barratt-Boyes, then one of the doyens of surgery. He had written **the** book. It took some months to regain any street cred.

In surgery, you are watched with equal intensity. I described it once⁴ as like 'learning the violin in public'. Every piece of fingering watched, and false notes remembered. The surgeons I was working with were amongst the best, and I was very conscious as the new boy that I must not let the side down. Whilst cardiac surgery comprises a reasonably well known series of steps, each operation has many moments of tactical decision making, subtly different approaches and periods of intense technical difficulty. It was not uncommon in the 80s and 90s to come across anatomy that was not quite what one was expecting (imaging was less sophisticated), and you would have to adapt quickly and creatively to the circumstances. When the heart is stopped to perform an internal repair, there is also a time limit during which you must complete the repair before the heart begins to deteriorate. Thus, clarity of decision making, communication with the team and rapid, accurate technical performance are critical. The anaesthetists have seen it all before, including all the best surgeons. You soon knew how well you were doing by the air of confidence or otherwise they exuded or by the sudden presence of your senior, summoned by the anaesthetist who might feel you need, shall we say, a little guidance. That makes some surgeons feel threatened or mildly paranoid, but to me it reflects a well-functioning team keeping the needs of the child at the front of its collective mind, and providing support at the correct time. You can only get good outcomes from an effective high quality team supporting each other.

Working with so many people from so many places, and seeing and hearing how things were done elsewhere made me very interested in finding ways to compare our outcomes. I was one of the founding members of a group of European congenital heart surgeons (ECHSA), and we decided from the start to collect all our outcome data to one database. We funded this out of our own pockets. This was the early 1990s, and computers were slow and rarely networked. Database construction was not as easy as it is now, and there were multiple problems to be ironed out in describing both what was wrong with the heart and what could be done about it in terms a computer could manipulate. I worked with many brilliant people from around the world including Bob Anderson from London, Jeff Jacobs from Florida, Rodney Franklin from London, Bohdan Maruzweski from Warsaw, Francois Lacour-Gayet from Paris to agree an uniform international nomenclature and a series of data definitions. Our early efforts have been developed by teams led by Jeff, Rodney and Bohdan, until we now have two large registries in Europe and the USA, collating almost 1,000,000 patients' data. Public exposure of results has helped many units identify areas for improvement and changed national policies⁵⁻ ⁷. The coding system evolved by this nomenclature group will become the WHO standard ICD11 next year. Whilst I have not done any legwork on the project for several years, I remain very proud of what we started in a dark and dingy office 25 years ago. To know how much improvement is possible, one must always be aware of who is best in class and make an effort to learn from them. I believe that is what the registries have taught us and why making outcomes as public as possible is such a good thing. Cardiac surgery has been at the forefront of publishing its outcomes, mainly because we always thought it was the correct thing to do, but also because of the Bristol heart scandal which made clear the importance of accurate and complete data collection to protect the public. Many specialities still do not publish outcomes in a way that allows patients or referrers to make effective choices[†].

Life as a Consultant

Things changed when I became a consultant. The quietest time of a surgical consultant's life is immediately after appointment, you have no personal caseload and your reputation is still to be earned. This hiatus presented an opportunity to visit other great centres and see how they did 'it' on their turf. My senior colleagues each had a phenomenal network. They helped me set up visits to Boston, Chicago, Birmingham Alabama, Duke University in North Carolina, and Loma Linda in California. It was an extraordinary experience. I got to meet the greats in the field, and arriving as the 'new boy' at GOSH was treated not as a student, but as an equal. I saw the same operations being done in several different ways, the details of which are beyond the scope of this lecture, but

[†]This topic is discussed further here <u>https://www.gresham.ac.uk/lectures-and-events/how-to-choose-a-doctor-or-surgeon</u>

which were sufficiently different for me to realise that there was a great deal of work still needed to identify the **best** way. Even in cardiac surgery it seemed there were many ways to skin the cat. It was a further 3 months away from home. There were no mobile phones, no Skype, no Internet. My children were 3 and 1.

I had to deliver lectures in each place; an early exposure to public pain. And brutal American questioning at some crazy hour of the morning, often at the weekend. I saw the good and the bad sides the American health system. The scale of investment that was in place for some, and the extraordinary poverty of others, often excluded. Some of the chief's offices were bigger than the whole suite of cubicles in our Portakabin at GOSH, and the equipment was staggering. There was much to learn; neonatal surgery from Boston; outcomes analysis from Birmingham; risk management in Chicago; research structure in Duke; and neonatal transplantation and a radically different way of running the heart lung machine in Loma Linda.

Loma Linda was the home of Len Bailey, a wonderful gentleman with the kindest heart, and an obsession. I arrived there just a few months after the controversial baboon heart transplant into baby Fae. It was very affecting to be in a community where it appeared that the whole population was four square behind this approach, and to realise that all the highly critical press I had read in the UK did not reflect the extraordinary dedication to human life of this largely 7th day Adventist city. There were probably few places in the world where this operation could have been done. I still do not agree with the underlying principle nor the incomplete science that led up to it; issues which I have discussed many times with Dr Bailey over the years, but I respect him hugely as a human being. Last year I met baby Fae's mother for the second time. Despite the terrible loss of her child, and the associated, sometimes vitriolic, criticism over the years, she remains certain that she did the right thing and immensely supportive of the efforts made for Fae and others.

Returning to GOSH my workload rapidly increased. I also operated in Newcastle for many Thursdays until they found another surgeon, and my lists soon filled. The days quickly became long again, and the nights busy. I was, like all other new surgeons, terribly anxious that my patients did well and keen to fend off any problems at an early stage. Within two years we began discussing whether or not there should be a transplant programme at GOSH. Forever searching for improvement, my colleague Marc de Leval organised a training programme for us with the Papworth team and we learnt to transplant, with all the extra out-of-hours commitment that requires. Marc and I worked together on the transplants for the next 25 years. At the start, I went with a small team to collect hearts from all over the UK and Europe. We drove ourselves, collected the heart, drove back and then helped with the insertion, and often the ICU care afterwards. The rest of the units work slowed briefly but did not stop. I was on call like this, 1:2 until we hired another colleague, Victor Tsang, in the early 2000s.

I am going to talk about the medical aspects of heart transplantation in November, but there is little doubt that the mechanics of transplantation were exciting in those days. I have often thought that everyone should have the experience of being driven in a police car blue-lighting to Heathrow from Bloomsbury in the rush hour. I remember coming up Constitution Hill towards Hyde Park Corner at high speed and realising that there was no way we were going to get around the roundabout. The police car carried straight on through Wellington Arch, but my brain and stomach were heading in a different direction.

On another occasion, we flew to Londonderry, were driven by a man with a very strong Belfast accent in a Transit van, needing to cross the border to go to Letterkenny. The driver, with his load of English people, got lost in the staunchly republican area called the Bogside, and all the directions we were given proved circular, and it took ages to get out. It was truly frightening. By the time we reached the Border, the Army took the view that we should be carefully searched and there was a huge delay. When we arrived at the hospital in Ireland, the donor had deteriorated and we could not use the heart.

The stories of the donors were tragic. One of my first retrievals was from a child who had been placed by his mother in a baby walker to move around on an unfenced flat roof. On another occasion, the donor hospital was unusually silent. The donor was the child of a senior manager and had become buried in sand on the beach. The manager found out what had happened whilst on a tour of the emergency room. There are many such stories, but they serve to remind you that the heart you are collecting belongs to someone, and must be treated with infinite respect.



Previously I have found the duty aspect of it is hard to get over, even to close friends. The concept of 'on call' seems to fox many people. They seem to have a mental picture of a nice chat on the phone when called out from dinner or perhaps a quick decision via a phone call from ones bed. Not so. On call in paediatric cardiac surgery means being ready to go at any moment, from wherever you are and whatever you are doing. And then being away for however long it takes (days sometimes) before coming home exhausted, drained and useless for anything else. And then up the next day for the same again. Covering every other weekend meant Friday morning to Monday evening, and one was often needed. One can become a poor partner and a poor parent. My son Toby once said, when he had an unpleasant but not serious illness, "You have to be on a ventilator for Martin to think you're ill". That still tears me apart inside. It is important for anyone entering this field to understand that your family will be part of your work, however unwillingly. You will often be absent; physically and mentally.

That said, things have improved dramatically over the last decade. Rotas are kinder, with more consultants per centre; junior staff have restricted hours (48 per week instead of the 110 to 120 I had to do as a junior); prostaglandin allows us to postpone surgery until waking hours; and intensive care is now run by intensivists, themselves on shifts. Technology has improved enormously, not least the arrival of the mobile phone which at least means you can take the dog for a walk. Information and images can be sent via the cloud so you are more able to make decisions remotely and we have all gained more experience and have better protocols.

But we have also extended what we can do, to conditions we couldn't treat when I started and to smaller and sicker babies. Results have improved dramatically and expectations have risen even more. These impose new stresses, particularly with public scrutiny of our results. Consultants still have to get out of bed, although less frequently, but when in they must be obsessional and precise in act and in communication. The operations may be largely the same, but reproducing the currently outstanding results day after day is tough. Some surgeons struggle to cope with this pressure, even though they may be technically proficient. The more complex operations force units down the route of sub-specialisation to optimise outcomes, so cross-cover has again become an issue in some places.

Innovation

GOSH is a specialist (tertiary and quaternary) hospital, taking referrals from other children's hospitals and specialists. It is a centre of excellence for many specialties and deals with many of the rarest and most complex conditions children can have. I have hardly ever seen the same thing twice, and have learnt something every day of my clinical life. At GOSH, there is always an expert along the corridor to ask, and you gradually gain confidence in managing the most extreme cases and can offer hope to families who have had none. The skill levels across the board are of the highest order, and it is a pleasure to work with and learn from other disciplines. So many times, I have met families who say, "It was a relief finally to get here". It has been a privilege to try and live up to those high expectations.

GOSH is joined at the hip to the UCL Institute of Child Health. This creates a living bond between research and clinical practice, allowing us to bring new developments to the patient as quickly as possible, and to take questions we raise in clinical practice back to the lab to find more effective answers. It has been a privilege to be in an environment where research is not just tolerated but fostered and indeed expected. GOSH-ICH competes with the other great children's hospitals in the world. It was incredibly intimidating to find oneself playing for a team in the Champion's League, but such competition has proved very effective in driving up standards here and everywhere.

When I came back to the UK as a new consultant after my trip to the USA, I was highly motivated and eager to apply many of the things I had observed. The open nature of our MDT meetings, the JCC, meant there was a weekly opportunity to debate various approaches to care, and people were always returning from an academic meeting somewhere in the world with suggestions for improvement of further research. If you could make a good case for change, and could subsequently back it up, the team was well up for the application and study of new ways. Research was part of the culture of the place and there was a uniform desire to improve. I was given freedom to innovate, and encouraged to apply for funding and carry out research. A unit or hospital that is involved in research is likely to be safer and better organised than one that is not. Research challenges

conventional thinking, improves record keeping and accrues evidence. Follow up is more detailed and almost always the outcomes are more visible.

We made many changes to cardiopulmonary bypass, finding ways to reduce capillary leak, minimise organ damage, simplify the procedure and identify ways to study the distribution of blood to the brain during surgery. Much of this was possible because of the International nature of the specialty and the fact that GOSH was seen, by surgeons throughout the world, as a great place to train. The fellows who came from overseas were always eager to join our on-going research programs and almost without exception brought something new and better to the table. The were well-informed, analytical and challenging. It was impossible to rest on your laurels. They questioned everything and taught me always to look critically at the way we do things.

These fellows have become my long-term International research partners and most of them now lead major international units. One of the most surprising and enjoyable aspects of my life as a cardiac surgeon is this very internationalism. I have had the privilege of operating and teaching throughout the world, and many of the doors to this life were opened by people whom I was involved in training. It has been wonderful to see these surgeons grow into world leaders, innovators and trainers in their own right and to realise that I may have played a small part in their development.

Paediatric cardiac surgery is a small discipline. Everyone in the business knows everyone else, often throughout the world. Like my peers at GOSH, I have operated on most continents, lectured all over the world and I feel privileged to have been able to do so. It remains possible to become an expert in some part of the speciality, and this creates the opportunity to travel, teach and learn Internationally, and thus sometimes to make a difference in more than one country.

Learning on the Job

Training as a surgeon at senior level is an interesting issue. Surgery remains a craft, involving a significant amount of dexterity, haptic memory and three-dimensional understanding. Traditional surgical training requires you to assist the 'teacher' at many operations and then be allowed to do an increasing proportion of the procedure. But to be an assistant in paediatric cardiac surgery means that you are (usually) on the opposite side of the table to the senior surgeon. And the heart of a small baby is deep within the chest cavity, so it can be really hard to see what the surgeon is working on, let alone the detail of what they are doing. And you are watching an *inverse* image of what the surgeon sees. Reconstructing the correct view in your head is prone to risk.

There are many styles of surgeon who carry out operations in subtly different ways; in the same way classical musicians play an individual composer's work in subtly different ways. In music, the pupil chooses the teacher that suits them. In surgery, that is rarely the case. The teacher chooses the pupil, and that can sometimes lead to clashes of style. For example, one brilliant young surgeon who came to train with us simply could not operate with one of my colleagues who found the young surgeon's natural operative style to clash with his own. It was a nearly career-ending clash. But after some toing and froing, the young surgeon came to work with me, and our surgical styles meshed well. In fact, I found operating with him a real pleasure, and he ended up a consultant at Great Ormond Street before going back to lead (successfully) a major unit in the USA. This experience was very valuable to me. Personality and physical operating style ARE important in establishing training relationships, and this needs to be recognised. Training for a high-level skill can only partly be formulaic, and training schemes must include an element of flexibility if we are to allow our young surgeons to flourish.

The importance of the harmony of a successful relationship between surgeon and assistant cannot be underestimated. But there are equally important relationships which make a cardiac operating theatre function well, and which also form the basis of a very happy working life. The first of these is the relationship with the theatre scrub nurse. This is a nurse whose job is to hand you instruments in the correct way at the correct time, and to keep organised and effective care of the instrument table. As a surgeon, one is concentrating hard, usually silently, and working at the apex of a small narrow cone. Often you need a particular instrument to help with part of the procedure, but struggle to remember what it is called. A great scrub nurse (and I have worked with several outstanding ones) will be watching closely over your shoulder and will gather together a few instruments he or she thinks you might need. As your hand comes out in request for an instrument, the nurse will select one and place it in your hand, in exactly the right position for you to be able to use it. No words need to be spoken. It can and probably should look like an exquisite and silent ballet. There is an old saying in surgery; 'Don't give me what I ask for, give me what I need'. The great scrub nurse is always one step ahead of even this order.

You build strong relationships with the perfusionists who run the heart lung machine. They are vital, clever and very practical. Great problem solvers. We used to joke that if ever you needed to escape from a German prisoner-of-war camp, they would be the ones to design the tunnel, find the way of hiding the earth and be able to get hold of a German uniform or false passport. Their work makes the patient safe., and they all have the leadership skills to dominate the room if they need to deal with an emergency.

This flux of leadership also applies to the anaesthetist, the relationship with whom is critical to good surgery. The anaesthetist is not just keeping the patient's pain at bay. She or he is a physiologist, using drugs, fluids and ventilation methods to adjust to circumstance and maintain excellent flow of oxygen and blood around the child's body. A decisive, clear and supportive anaesthetist with whom you feel able to discuss a patient's multiple problems can be a source of great strength. I have been lucky at GOSH to work with some of the best, and their commitment to the safety of the patient has been critical to success as the surgeon concentrates on the plumbing.

Ethics

A paediatric cardiac surgeon will face many ethical problems during their career, either in decision making for an individual patient or for groups of patients with particular conditions. I have faced several in my time.

There is a congenital abnormality of the heart called atrioventricular septal defect, AVSD or sometimes AV Canal. It is characterised by there being confluent holes between the two atria and the ventricles and a single valve across the middle of the heart instead of a separate tricuspid and mitral valve. It is relatively common in children with Down's syndrome. It is hard to believe now, but when I became a consultant, several units in the country were not offering surgical repair of AVSD to children with Down's syndrome. It was judged that their life expectancy was low and that their quality of life because of Down's syndrome did not justify repair. Instead they were allowed gradually to die of pulmonary hypertension and heart failure. By repairing the condition in the first few months of life in one stage, the outcome was significantly improved and both quality and quantity of life have improved. Many patients were referred to us and to Birmingham because we would operate, and the lives of many parents was improved by limiting the disability of their children.

There were similar debates about the introduction of several treatments for conditions judged irreparable in earlier times. I described many of these in an earlier Gresham lecture[‡]. Nowadays, almost all conditions are treatable according to recognised protocols and with established levels of risk. The ethical debates we have now relate more to the assessment of levels of risk at the very high end and to the management of patients whose treatment has already been commenced, but in whom the outcome is judged to be very poor. All surgeons feel a strong internal need to save the individual child, but sometimes it may be better for child and family that the fight be abandoned, if there is judged to be too much suffering. Fortunately, the speciality of palliative care has evolved and we are able to call on them earlier in the course of treatment to help provide other options to the family. Often neither surgeon nor family can speak the word 'futile', and it needs to be expressed by people trained in what is a difficult but necessary art.

Most surgeons, in my experience, are of course very reluctant to admit defeat. I think that is to be expected. However, on occasion I have seen surgeons (especially in the US) whose reluctance is not for the benefit of the patient, but rather to ensure the integrity of their own individual published outcomes. In England, outcomes are now reported at for at least one year after surgery, to some extent neutralising this effect.

Management

[‡] <u>https://www.gresham.ac.uk/lectures-and-events/the-ethical-challenges-of-new-treatments-in-children-could-we-do-now-what-we-did</u>



I have described how important is the teamwork associated with cardiac surgery. For teams to be effective, they must have several well described characteristics, and to be able to function, develop and innovate within a wider hospital environment they need leadership and management. As you climb the greasy pole of consultant life, more and more demands are placed on you to build and lead such teams and thereafter manage parts of the business of the hospital. Cardiac surgeons often have skills which either lend themselves to taking on management roles (after all, team leadership in the operating theatre is a core part of the job) or the self-belief that they should be in charge, even if they lack the skills. A cardiac surgeon must be decisive, adaptable, have clear goals, be resilient, driven, and able to both give and accept criticism. Sadly, most surgeons fail on the last point!

The only way to make change in a department or hospital is to get involved, understand the system and use it. You cannot get a new piece of kit without having a good evidence base that it works, an understanding of the cost benefit and some idea of where the money might come from.

Over time, the work we do changes as new demands are placed upon us, or new techniques develop. New teams may need to be formed, e.g. transplant or tracheal, old ones dissolved and existing boundaries may need to be broken down. You will always meet resistance, but if you want change you must lead, communicate and influence. And learn from those who do it best elsewhere. We did this for transplantation, tracheal surgery, MRI and a variety of other sub-specialties. Each required service development, business cases and strong argument. Fighting for innovation **IS** management, and one has to learn these skills to improve the practice. There is increasing interest in simulation training for teams, a move which I wholeheartedly welcome. Such simulation should not be limited to medical teams, but include the **whole** team which looks after the patient, managers included.

There is a feeling abroad that the NHS is over-managed and over-scrutinised. It is true that certain parts of it have become extraordinarily complex and almost Byzantine since the purchaser:provider split was introduced in the 1980s and even more so after the Lansley reforms of the first Cameron government. But for hospitals to work they need effective management, good processes and skilled organisers. Many doctors are good at vision and to some extent strategy, but I have seen few who really understand process or flow in any detail. The managers in hospitals are often highly intelligent, utterly dedicated and grossly undervalued. They are often desperate to improve how systems work, but waste a great deal of time simply managing inadequate capacity to meet demand or feeding the beast higher up the NHS which demands greater and greater information without adequate IT to support them. Managing the cardiac division was one of the hardest jobs I have done, and contrary to popular perception, there is no extra pay and you still have to do your day job. The satisfaction comes from creating environments where patients and families are happy and satisfied, making improvements, supporting innovation, hiring well and watching others become great. Always hire someone better than yourself.

There are many things I would change about how hospitals work; more standardisation of process, massively improved IT, linking of financial and clinical data so that we could understand and reduce cost, freeing up resources to care for more patients and liberate capacity. I think hospitals could do with a touch of discipline in some areas and even more concentration on the patients' needs, even in such simple things as Wi-Fi, on-line booking and food. I have had the opportunity to be engaged in all of these things and know that if I had not done, some things would not have happened. The experience has added to my skills and increased my humility. I very much respect many of the hospital managers with whom I have worked....and they work just as hard as doctors and they are just as dedicated. When I became co-Medical Director at GOSH, there was a feeling that I had 'crossed to the dark side', and without changing my views, I suddenly became the enemy to some. It saddens me to hear dedicated managers being criticised by intolerant doctors or by the media. The current system is not their design but a product of political interference, excessively complicated reform and a long period of austerity. As Polly Toynbee once pointed out, "The one outcome that is never measured in the NHS is the outcome of what politicians do".

As a cardiac surgeon and an administrator, I have been very frustrated by constraints on capacity and perpetual reorganisation, particularly the Lansley reforms. There was a period a decade ago when investment was relatively good and the focus was on the safety and quality of care, concentrating on the patient's needs. Since then, we have slipped down the league tables as a system. I am proud that GOSH has maintained the highest quality throughout, but we have more demand than we can cope with and our staff are often exhausted. Cost



savings are always possible, but systems and processes need to be right to deliver those savings[§]. The fragmentation of the NHS, lack of adequate interoperable IT, an obsession with localism and the lack of political will to close inappropriate services have conspired to make daily life much more complex and demanding than it should be now that we have resolved many of the therapeutic decisions for patients. We need some spare capacity and rested staff if we are to deal effectively with urgent and complex cases. To discover that the ICU is full again causing cases to be cancelled at the last minute is not due to bad surgery, or bad patient management but rather to bad national planning and inadequate investment. We desperately need more ICU beds in paediatrics. Cardiac surgery has done very well over the last decades. Results are now outstanding, and of course public expectations have risen. Yet, we are increasingly reliant on charitable funding, and that should not be the case in a wealthy, modern and ambitious society which cares about its future.

The Future

This has been a wonderful job, and I have few regrets about my choice of career. But things have changed. The glamour, excitement and perpetual innovation of surgery has calmed.

I asked one of my younger colleagues what advice he would give to a trainee interested in choosing paediatric cardiac surgery. His reply was interesting:

"If it is the one thing in work that makes you happy, the one thing that makes you get out of bed on a cold Monday morning, then do it. But if there is something else that makes you equally happy or even just a bit less happy, do that instead."

When I asked him why, he answered,

"The relationships have changed. You are now much less respected as a surgeon, you are more managed, more controlled by others. The pressure for perfection is massive and every minor error is scrutinised often by people who haven't a clue how hard it is to do what you do. Anyone doing this surgery understands how tight the margins are; placing a stitch less than a millimetre away from the ideal place may have devastating consequences. This is surgery which demands a very high level of technical skill, and the ability to perform that skill under scrutiny and against the clock. It is tough. Yet you're paid the same as a dermatologist who never gets out of bed and who has so much less stress. On top of that there are so many system problems, particularly with lack of capacity to meet demand that you have to spend half your time managing disappointment".

This must be a growing perception. There are hardly any UK trainees entering the specialty. And there is an overall shortage of applicants. It seems they are looking for more normal lives or perhaps are attracted to the areas of medicine which are currently either highly innovative or intellectually challenging in a different way, for example interventional radiology or oncology. This audience has heard my views on this before, but I am happy to state them again. To achieve an appropriate work:-life balance for people who do paediatric cardiac surgery, they must work in fewer, larger centres; with enough staff; where research is fostered; where time is made available; and where support is continuous. Training must be more sophisticated and include team simulation. We must concentrate on the well-being of our junior staff if it is to remain Nice Work.

For me, this has been a perfect job and a great privilege in every way. Working in a Children's Hospital is, in my experience, much more fun than working in an adult one. There is a natural human need to make life good for our children, and that is visible every day in the dedication, cheerfulness, goodwill and love expressed by the staff. What is not to like about sitting and playing with a child in the middle of the day, seeing them smile and helping them understand what is happening. The children are our *raison d'etre*. A child's smile, tear or searching question will always ground you, and daily remind you of why you come to work. It is an important sign of a civilised society to care well for its children. They are our future. Michelle Obama put it very clearly last week^{**}; "*We need everyone to care deeply about our kids.*". This is a philosophy which seems to me embedded in the staff at GOSH. They strive to make the children as happy as possible, and I am proud to say that, as you walk around Great Ormond Street Hospital, it is rare to see an unhappy child.

[§] https://www.gresham.ac.uk/lectures-and-events/doing-more-for-less-paediatric-cardiac-surgery-after-the-financial-crisis
** https://www.theguardian.com/us-news/2017/may/12/michelle-obama-trump-school-lunches-childhood-obesity

These Gresham lectures have given me an opportunity to reflect which is a yet another privilege few are given. I hope in these lectures to have drawn your attention to the issues which challenge us in the field, and given you an insight into our world. In this lecture hall, I have met families whose children I treated, and also many of the babies I operated on, now adults, have come up to me at the end of lectures to say thank you. It has been incredibly moving, and an immense pleasure.

I can only thank all those who have supported me. Primarily of course my family, but also all everyone at GOSH, the ICH and in Newcastle. But I would not be here now if it were not that children needed someone to repair their hearts and I was lucky enough to find I could do it. That the children and their families have trusted me to do so has been an honour. It really has been **Nice Work**, and I got it.

Thank you.

Special thanks must go to all the patients and families in whose care I have been involved. To all the amazing people I have worked with in this speciality; too many to list, they know who they are and how much they have helped me. To those teachers who believed in me at each stage of my education, sometimes against all the evidence! To my colleagues all over the world who share experience, criticise and stimulate. And most of all to my family, who have had to put up with so much to make this possible.

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