1.1 On being a patient 3

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ESSENTIALS Those who practise medicine should remember that we are all pa- tients at some time, most likely at the beginning and end of our lives. We therefore begin this textbook with an account of encounters with the medical and nursing professions, written by an outstanding doctor, medical historian, and leading clinical scientist. After a highly distinguished and eventful career which spanned the introduction of the British National Health Service in 1948, Christopher Booth died in 2012, aged 87 years. Latterly, he experi- enced the protracted misery of illness punctuated by repeated sur- gery; but to the end he retained his intellect and penetrating wit. His piquant observations are a challenge to us all as we try to provide care for our patients, as is his parting shot: ‘If you are a physician, no matter how important you may think that you are, you should, so far as your own illnesses are concerned, consider yourself a layman.’ Introduction We are all patients sooner or later, but particularly at the beginning and end of our lives. A general practitioner brought me into the world, a second twin, by manual removal when my mother was suffering from uterine inertia. Later, as a four-year-old, I can recall being in- jected against some form of infectious disease and passing out cold on the floor. There were then many infections to which my gener- ation was susceptible. Chickenpox, mumps, and measles were fre- quent. During the misery of measles I remember seeing the flag on our nearby church flying at half-mast for the death of King George V. Our doctor, the one who had delivered me, was a tall, distinguished man, smelling, as they all did in those far-off days, of ether. Later I con- tracted scarlet fever, a streptococcal illness of importance in those days before antibiotics. I was kept in strict isolation at home, with a resident nurse to care for me and daily visits from our general practitioner. Between those childhood days and the years of maturity, I was but rarely a patient. There was a hazardous episode during training as a naval diver when I had an alarming allergic reaction to the sting of a jellyfish (Portuguese man-of-war). The main symptoms were caused by severe oedema of the throat, and breathing became difficult. I had no idea then, long before I became a physician myself, that the large dose of morphine given by the naval doctor might well have exacer- bated the respiratory distress. Beyond that, as a young man I was only a patient for a brief period with glandular fever. I have been fortunate to escape those chronic conditions such as multiple sclerosis, Crohn’s disease, or rheumatoid arthritis that blight young lives so terribly. It was not until I was in my fifties that I developed any significant illnesses. I had intermittent atrial fibrillation, which usually subsided with antiarrhythmic drugs. My blood pressure was normal and has re- mained so. There were repeated electrocardiograms, but no attempts at cardioversion by DC electric shock. For the first time I began to make visits to hospital outpatient clinics or enter the sumptuous rooms of those who undertook private practice. It was this experi- ence that made me realize that the particular feature of being a pa- tient means having patience. One came to accept

that so much time is spent waiting—for an appointment, for a blood test, or an X-ray, for a consultation, or for drugs from the hospital pharmacy. As the years go by, you should realize that, like your patients, you are more liable to afflictions which may be truly frightening and threaten your life over prolonged periods. My next encounter with medicine in practice came about entirely by chance. I had been retired for some years when my partner encouraged me to have a ‘check-up’. The excel- lent lady general practitioner was not one of those many who spend more time staring at a computer screen than they do looking at you. She examined me carefully, found nothing amiss but despatched some blood tests. These too were normal with one exception, a test with which I was then unfamiliar. The blood concentration of prostate-specific antigen (PSA) was 15 µg/litre and thus above the healthy range. I was informed that this suggested the presence of a symptomless cancer of the prostate and although I was reassured that the significance of the finding was uncertain, a subsequent prostate biopsy revealed that there was indeed cancer of the prostate, apparently localized to the gland. The question therefore arose as to what should be done. Much today is made about choice; perhaps this has value when there can be truly an informed discussion, as subsequent events in my case show. So far as I was concerned, I had no interest in where I should be referred for treatment. My doctor could advise me about that. Nor had I much interest in choosing between the options available—surgery, radio- therapy, or hormonal treatment. It was for my advisers to recommend what they thought was best. It was only in later years that I realized that 1.1 On being a patient Christopher Booth† † It is with great regret that we report that Christopher Booth died on 13 July, 2012.

4 SECTION 1 Patients and their treatment the choice of radiotherapy was unfortunate. At the time, daily treatment as an outpatient for more than six weeks was a tormenting experience since the resulting radiation cystitis caused excruciating pain. I was constantly reminded during those days of the urologist who prayed nightly to his maker: ‘Lord, when thou takest me, take me not through my bladder.’ In the end the symptoms subsided. The PSA level returned to normal and has remained so. Mercifully, the cancer had been eradicated. I soon devel- oped severe muscle pain—diagnosed by a rheumatologist as polymyalgia rheumatica and which required treatment with steroids. Nothing will ever convince me that these symptoms were not the result of the radiotherapy. These events took place during my 70th year. A few years later, while in manifest good health, illness suddenly struck again. One evening, out of the blue, I developed severe upper abdominal pain. In the ab- sence of an out-of-hours service from the local general practice, at midnight we attempted to obtain medical advice from NHS Direct on the telephone—this was a fruitless task made very trying by ‘language difficulties’. I finished up in the accident and emergency department of our local hospital. There, a very competent Asian doctor treated me with pethidine: and there too I first experienced lying on a trolley for the rest of the night. Lying on a trolley is no great problem for a patient blissfully enjoying the delight of repeated injections of pethidine but it is extremely dispiriting for one’s partner. Deeply troubled by my illness, seated in a small and uncomfortable plastic chair, my wife had nothing to do but watch and wait hopefully for the dawn. A week in hospital taught me how to manage my life while attached to an intravenous drip, which had to accompany me at all times. It turned out that I had acute pancreatitis, possibly associated with a gallstone. The pain soon subsided and, apart from one other minor event, has not recurred. All remained well for four or five months. Then, attending a clinic for a follow-up appointment, I found out why, for a little while my wife had noticed that I was thirsty and polyuric. She, of course, had made the right diagnosis, which my medical adviser at once recog- nized when he smelt the acetone on my breath and found my blood sugar to be in excess of 30 mM. I was

immediately admitted and the diabetes was brought under control by intravenous therapy. On this occasion I was admitted to a geriatric ward where the noises at night generally made sleep no more than an aspiration. One particularly un- fortunate man, suffering from expressive dysphasia caused by a stroke, kept shouting in frustrated attempts to make himself understood. Becoming a diabetic at once changes your lifestyle. You find out how to control your blood sugar, initially on oral medication. But soon, as is so often the case, you require subcutaneous insulin and you now have to learn how to inject yourself as well as keeping to a strict diet. You also have to ensure that you avoid the unpleasantness and fear of hypoglycaemic attacks. In addition, you may require visits to the foot clinic to ensure you neither develop ulcers nor infected toe-nails. If, in the case of that illness, it was a matter of one thing following another, my next and most serious medical encounter was even more Odyssean. By my 82nd year, I had thought that the prostate cancer, 12 years after radiotherapy, could safely be forgotten. The PSA con- centrations had remained within the normal range and I seemed in good health. But then haematuria developed. Cystoscopy as an out- patient failed to identify a source for the bleeding and while waiting for an appointment for an inpatient cystoscopy, I suddenly developed clot retention. It is no pleasant experience driving through metro- politan rush-hour traffic during an attack of acute retention. Nor was attention at once forthcoming in an accident and emergency department, dealing as usual with the overwhelming evening intake of drunks and dropouts. Finally installed once more on a trolley, a junior house officer attempted the necessary catheterization. Only after repeated and painful efforts is a more experienced registrar sent for; he at last blissfully relieved the obstruction. Then again, the long wait—and finally, admission to a high-dependency ward. I remained in hospital for treatment over the next three and a half months. The events of that first week in a high-dependency ward set the scene for what was to happen during the next months. A regime of constant bladder washouts was instituted in the hope that the haematuria would subside. Several drugs were tried, all to no avail. There was obvious re- luctance to undertake surgery in an elderly patient for a condition which showed no sign of being malignant. So in due course I was transferred to a single room in a urological ward where the haematuria persisted des- pite continuous bladder washouts. Maintaining the flow of fluid from two large containers hanging on a drip stand became one’s constant concern, nurses not always leaving enough fluid supplies, particularly at night. If the flow ceased, clot retention would recur. For a brief period I was sent home in the hope that the symptoms would subside. But it was to no avail—as was the search for the cause of the bleeding. Two careful cyst- oscopies under general anaesthesia failed to identify a bleeding point, an- other reason why there was reluctance to consider surgery at that time. One soon became used to a ward routine that scarcely varied from day to day, with the exception that at weekends nothing ever seemed to happen. You might be gently woken by a kind nurse from the Philippines wanting to give you something but whose command of English might not be fully up to the task. You would be increasingly less surprised to see the unfamiliar blank wall that had been there when you drifted off to sleep. You would at once be aware of noise, trolleys being pushed along corridors, the clatter of metal containers, and sometimes the cries of the afflicted. You have breakfast, the same cereal most days, sometimes por- ridge. You are given the morning’s drugs. A venesector takes your blood every day, the veins becoming progressively less easy to find. Your blood pressure, oxygen saturation, and pulse rate are measured on a machine every four hours or so and it may be necessary for a drip to be inserted, a task undertaken better by some than others. Your insulin dosage has to be adjusted, depending on the results of your blood sugar obtained by pinprick. Your bed is made, your body washed. You sometimes see the intern who has the care of you, but they change frequently. Then there is the consultants’ ward round. Instead of a single individual taking

care of you, you find that up to five consultants, and their acolytes, visit to- gether. Invariably courteous and considerate, you learn to hang on every word. There are those who find the recumbent position of the patient in bed, in the presence of massed ranks of consultants, to be demeaning. I have preferred not to acknowledge my obvious inferiority but to im- agine myself a mediaeval potentate receiving his courtiers. Then, at last, another surgeon is brought to see me. The waiting is now over. Briskly and unhesitatingly, he decides to operate within three days. I am lucky—he is one of the best in the country. The operation is to be a total cystectomy and prostatectomy, the creation of an intestinal pouch to replace the bladder and transplantation of the ureters into this pouch. One can easily understand why my advisers had been so hesitant to inflict such a procedure on an individual in his 82nd year, irrespective of my status as a former Professor of Medicine. Fortunately the surgery is brilliantly successful and we now have a diagnosis. The pathologist reports that there are no specific bleeding points in the bladder but that there are signs of widespread radiation damage. As with my diabetes, one thing has again led to another: the diffuse pathological bleeding was caused by that course of radiotherapy given so long ago. Surgical success depends on the support you receive before and after the operation. Languishing in hospital, I had lost a considerable amount

1.1 On being a patient 5 of weight and nutritional advice from a gastroenterologist was needed for recovery. There were other complications. My thumbs became septic because of a faulty technique in obtaining blood for sugar estimations and both were later shown to be infected with the near-ubiquitous methicillin-resistant Staphylococcus aureus (MRSA)—as was a small unhealed focus in my abdominal scar. More drugs—this time, anti- biotics to control the MRSA. Still feeling weak and scarcely able to walk the distance from the kerb to my front door, I was sent home. I felt terrible that day and by evening had developed severe dys- phagia. Back in hospital I was soon drifting dreamingly in and out of consciousness; little did I know that my wife had been told by my ad-visers to expect the worst. By the next morning, however, the gastro- enterologists had done an oesophagoscopy and identified oesophageal candidiasis. I was treated with nystatin and soon recovered. Although the appetite took time to recover, I was able to eat again and returned home to convalesce. But it was to be a year or more before my strength fully recovered and for some months my voice was weak and husky. Certain memories of life as a hospital patient persist.
I encountered so many consultants during that time: seven urologists, a gastroenterolo- gist, a cardiologist to check whether my heart would stand up to surgery, a diabetologist, a rheumatologist to check my steroid dosage and the status of my polymyalgia rheumatica, as well as a dermatologist when a presumed drug eruption occurred. There was also the infectious diseases expert who treated the MRSA infection. Throughout, the international nature of the team who contributed to my care was impressive. Among doctors, nurses, porters, radiographers, and other staff, I counted mem- bers of 38 nationalities, including many nurses from sub-Saharan Africa and the Philippines—clearly countries favoured for recruitment to the United Kingdom and one wonders about their loss of national skills. Despite laudable attempts to make it tempting, hospital food was generally unappetizing and I depended largely on my wife for susten- ance: she brought in dinner with a small bottle of red wine most even- ings, and on this I survived. Yet above all, a patient depends on the support of friends and family, upon whom a greater burden lies than is often realized: my wife visited on every day of my incarceration—a task that she undertook despite her commitment to our household and her own affairs, when travel was not always easy and when, having arrived at the hospital, parking might be difficult. It is the doctors and nurses whom you meet every day who can do most to sustain your spirits. As a medical student in Scotland I was taught to treat a duchess or a dustman just the same. The patient should, of course, always be

treated with respect: I am convinced that this starts with their being addressed naturally using their surname (given name) rather than the all-too-prevalent belief that use of their first name would be preferred from the outset. Clearly this familiarity may come later—by invitation- and when desired by the name-holder. It is astonishing to see how frequently patients are offended by the pre- sumption of first-name familiarity, at least in hospitals in the United Kingdom; it is a behaviour perceived as institutionally controlling by adults of all ages and status—and not only by elderly professionals. But if the staff genuinely sympathize with your lot, spending time an- swering your questions and those of your family, you are greatly en- couraged. It is so often the little things which count. I recall being much moved and heartened by a young Zimbabwean nurse, who had cared for me during one of my hospital admissions and who later took the trouble to visit me in a far-off part of the hospital to see how I fared. Continuity of care is also important. Being under the care of an in- tern or nurse whom you get to know and who understands your illness is essential for morale. Having to explain your problems to a stranger who drops in for a brief uncomprehending visit after hours or at a weekend does nothing for confidence. There are also practical matters which may be overlooked. Whereas major interventions involving surgery, for example, may be explained scrupulously, staff doing ap- parently simple procedures such as venesection, cannula insertion, arterial puncture for blood gas determination or catheterization and the like, often forget that these activities also require explanation since they may distress anxious or confused patients—to whom the slightest invasion of their person rapidly becomes anathema. Anxious des- pondency also mounts when there is unaccountable delay in carrying out procedures that have been arranged: timely explanation can often mollify this distress but when it comes to the relief of pain, there is no excuse for delay—diagnostic or otherwise. The failure immediately to catheterize a patient with acute retention of urine is clearly unforgiv- able but as I learnt, is still regrettably common. Practical and important though many procedures are, requiring both skill and experience—for the patient, nothing can replace the compassion and sympathy that the caring professions owe the af- flicted. So many aspects of excellent practice stem from these simple human qualities, which thankfully survive despite the strong busi- ness ethic that pervades medicine in many countries today. Of the lessons that I have learnt, however, perhaps the most im- portant is that to be a patient entails, as the Oxford English Dictionary puts it, ‘enduring pain, affliction, inconvenience, etc, calmly, without discontent or complaint’. It is equally necessary to be ‘able to wait calmly’. In our later years, it easier to agree with this advice. After all, as a man reaches his eighties, he has little choice but to accept with equanimity the world of Shakespeare’s sixth age, when he shifts Into the lean v and slipper’d pantaloon, With spectacles on nose and pouch on side His youthful hose, well sav’d, a world too wide For his shrunk shank; and his big manly voice, Turning again towards childish treble . . . That passage accurately describes me in the immediate postoperative period, even to the urostomy pouch—but my voice has now recovered. I do not, however, wish to survive into the last of Shakespeare’s seven ages when we are doomed to ‘mere oblivion; sans teeth, sans eyes, sans taste, sans everything’. While I have so far benefited from the cour- ageous decisions of those who did not give up when the end looked inevitable but who saw that there was a ‘quality of life’ worth striving for, I only hope that common sense, compassion, and proper confer- ence with my nearest and dearest will be brought to bear when the seventh age draws nigh. One does wonder if such a perspective truly holds today—especially in wards for older people in modern Western hospitals. One other lesson remains. If you are a physician, no matter how important you may think that you are, you should, so far as your own illnesses are concerned, consider yourself a layman. FURTHER READING Booth CC (1987). Doctors in Science and Society. Essays of a Clinical Scientist. Cambridge University Press, Cambridge. Cox TM, Tansley EM (2012). Sir Christopher Charles (Sir) Booth. Royal College of

Physicians of London, Munk’s Roll, Volume XII (2005-) http://munksroll.rcplondon.ac.uk/Biography/VolumeXII. Lock SP (2012). Christopher Booth. BMJ, 345, e5768.

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