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ESSENTIALS If I have an acute curable condition, it is likely that your aims as a doctor and mine as a patient are aligned: we both want the problem to go away. But more people are now like me, living with disease rather than dying of it, and that change means that your role becomes less healer and curer, and more an advisor and supporter. A good model of care would be for you to see me, a patient with a long-term condition, as a full-time colleague on a job where you are only working part-time. Please understand that I am the primary caregiver, part of the healthcare team, in fact I am leading that team most of the time. I am very likely to access patient- sourced information (support groups, online forums, crowd-sourced information) and find this valuable, and you should not feel threatened by this. If you see me as a full-time worker with local practical knowledge, and yourself as an advisor to our project rather than leader, that may help us work together. Where we can, let’s learn from each other. Introduction I’m a patient. I have lived with a demanding long-term condition for more than 25 years. I also teach medical students with the help of other patient tutors and carers, and I am the BMJ’s Patient Editor. This means, first of all, that I have had to change the way I interact with the world, because my condition makes me different from healthy people. It means I have to spend a lot more time with doc- tors and other healthcare staff than most people of my age. But it also means that I have been given the chance to work with patients and carers from all kinds of backgrounds to ensure their experience and expertise is shared with readers of the BMJ, working with them to create educational articles that doctors can use to improve their practice. At the University of Oxford, I collaborate with medical educators to incorporate different patients’ and carers’ priorities in course design and lesson plans. I have also been lucky enough to be asked, as a patient, to intro- duce this book. I can’t represent every patient, carer, parent, or lay- person you will meet; but I can offer some insights into our world. Before I share what patients say they want you to know, here is some context. Healthcare is changing Learning medicine has traditionally meant a strong focus on acute medicine—diagnosing, treating, curing, and concentrating on one part of the body at a time. Traditionally, the doctor has always been the expert, the person we come to when something is wrong, so you can help make our bodies healthy again. Those skills are still vital, but things are changing in several key ways. What happens after diagnosis We have done so well in treating and managing communicable dis- eases that acute care does not dominate medicine in the way it used to (Fig. 1.3.1). Helping patients manage chronic conditions requires a different set of skills from those used in acute medicine. Diagnosis becomes only a tiny part of the story, because people can live with a long-term condition for a lifetime, and restoring people to full health is often impossible. Dividing the body up into textbook chapters be- comes less and less relevant because chronic illnesses can impact on many body parts at once. What happens after the patient leaves the clinic The other major change is the way laypeople can now interact with each other about their illness experience, and learn for themselves about their bodies. Patients themselves have changed the way they communi- cate, their willingness and ability to seek out and share information, and the opportunity to connect online in ways that the traditional medical model has never had to address before. We look things up, we ask each others' advice, we help each other when doctors cannot be there. 1.3 What patients wish you understood Rosamund Snow† † It is with great regret that we report that Rosamund Snow died on 2 February, 2017.

1.3 What patients wish you understood 9 There are more and more people living with conditions that stay with them for life, that demand their attention and management at varying levels. Some of us have illnesses that require daily work, some may be reminded of our ill health only when our chronic con- dition flares up, but we cannot be simply treated and cured as in the acute model of care. For many of us this means a different kind of re- lationship with our doctors than our parents and grandparents had. What patients want to teach When I ask people to identify the things we wish our doctors were taught, what do they say? What do they ask to be included on the medical curriculum? Rethink what you mean by listening to the patient Among people who submit patient-authored articles to the BMJ, one of the most common things they want to teach is listening: 'Read my notes. Take what I am saying seriously. Take my time and emotions seriously. Find out what matters to me, and address that.' All of this more or less adds up to: 'Listen to me.' Many authors say exactly that, in their suggested key messages, in the proposed title of their article, or both. I have to ask them to change the titles, or so many of them would be the same: Listen to me. Listen to the patient. Listen to the patient's family. Yet when I talk to doctors and medical students outside the clin- ical setting, they say they feel as if they are already listening. They know they ought to take patients' concerns and ideas seriously, even probe us for what we are feeling if we haven't volunteered it. In short, many doctors are trying hard to listen, but many patients still don't feel listened to. Why is there such a communication mis- match? I don't know the answer, but here are some thoughts for discussion by both sides. The clash of worlds A lot of medical training focuses on deciding which elements of the patient's story are key to diagnosis and treatment. Determining which elements have priority is usually left to the clinician. This can lead to problems, as can be seen by comparing the columns in Fig. 1.3.2. On the left, the priorities one might expect a doctor to choose when writing medical notes on a miscarriage. On the right, answers from women who had personally experienced miscarriage, when we asked 'what would you most like us to prioritize when teaching stu- dent doctors about pregnancy loss?'. Most of what is important to the women, and what they remember for the rest of their lives, is left out in the clinical record: it is unre- corded in the medical notes, not prioritized in service delivery, and not counted as part of patient safety. The medical notes are vital, but they are not the only things that need recording. The clash of agendas In teaching doctors I've found that one of the hardest things for them to take on board is the way patients feel when offered information they didn't ask for. Some patients who talk about communication 100% 90% 80% 70% 60% 50% 40% 30% 20% 10% 0% 1990 1995 Global deaths, both sexes, all ages 2000 2005 2010 2013 Noncommunicable diseases

Communicable, maternal, neonatal, and nutritional disease Fig. 1.3.1 Global deaths due to communicable and noncommunicable diseases. Data from Institute of Health Metrics and Evaluation (http://www.healthdata.org/results/data-visualizations).

10 SECTION 1 Patients and their treatment problems have asked their doctor for help on one topic, but were given information on something else entirely, because the healthcare professional felt the patient ought to have it. Often it is something the patient is told by every doctor, whether it is useful or not. If you have a patient who you consider to be overweight, but they are coming to see you about something else, giving them information about the benefits of losing weight can feel as if you are not listening to what they are saying. If you have a patient who has a long-term condition with risks of complications, and you insist on reminding them of these complications at every encounter, it feels as if you are seeing them as a disease rather than a person. Ask yourself: What is this person already likely to know? What did they come in for? Have I understood and answered that? ‘That can’t be true’ Sometimes patients don’t feel listened to because the doctor just doesn’t seem to believe them. If a patient tells you about something that has happened in their body—the interaction of one disease with another, the unusual reaction of their body to a particular drug, the fact that they feel ill even when a blood test says they ought to feel well—be very careful not to dismiss what they have to say. Evidence- based medicine has improved many aspects of care, but there are still a great many areas where evidence has not yet been collected, where patients themselves are collecting that evidence, or where your patient may be in a minority that responds in a way that a large-scale trial cannot pick up. In short, it may not be what you are expecting to hear, it may not be in this book, but that doesn’t mean it isn’t true. You as a doctor can ignore a symptom that you think can’t be real, but we as patients have to go home and continue to manage it. You have enormous power over many of us, because you control access to the drugs and equipment that keep us alive and well. We need you to keep on working with us to find a solution. What does this mean for the way you communicate with patients? In general, when I have talked to doctors and patients who feel they have got this relationship right, the doctor is not asking him or herself ‘what is wrong with this patient?’ or ‘what can I do for this patient?’, but ‘what is this patient asking me for?’ and ‘what does this problem mean to this patient?’ These seem simple changes to the way you listen and the nature of your questions, but if done correctly could transform the way you hear and act. What medicine records: Parity-0+0 Gestation-?12/40 Symptoms—bleeding, pain Scan result: 11 weeks, No Fetal heart Otherwise fit and well Diagnosis: missed miscarriage. Treatment options discussed —medical, surgical, conservative. Risks explained. What patients said they wanted doctors to know: The antenatal unit is not the right place for care: ‘My god that screwed me up seeing mums with little newborn and knowing full well my situation would end so badly’ Remember the rest of the family : ‘My partner had asked if he should stay in the room during the examination but no one bothered to answer him; I was left trying to talk him through what was happening whilst I was very frightened and upset’ Remember what miscarriage can mean: ‘[My GP] was amazing. She let me cry and then told me the two most important things—that this is a bereavement and I must allow myself time to grieve and that it was nothing I had done and there was nothing I could have done to prevent it. I will never be able to thank her enough for this as it was far more important than anything medical she could have told me’ Fig. 1.3.2 A woman has had a miscarriage: what medicine records, and what patients said they wanted doctors to know.

We don’t all share your interests or agree with your priorities When I was diagnosed with a serious illness, I had to become an expert in biomedicine, drug interactions, nutrition, and healthcare systems: I had to become ‘health literate’. The difference is that, unlike you, I was not interested in finding out more about it, I did not choose this life path, and nor am I paid to develop my skills in it; it’s something that was forced on me. Imagine the situation the other way around. You have a full day ahead of you doing your job as a doctor. In your spare time, if you can get any, you would also like to see family or friends. Now think of the thing you’d hate the most to have to spend your life learning about—stamp collecting, a children’s TV programme, fashion, cars, whatever you find tedious. Imagine that you have to expend a lot of effort working on this in order to function. You have to do it in addition to your job, even if it gets in the way and your colleagues get frustrated with the amount of time it takes up. You can’t even leave the subject alone at the end of the day, you have to work on it even when you’d rather be talking to your children. You have to take time off from your job or in your own time to go to clinics where experts in your hated topic test you on your skills (just as people like me have blood tests that show whether we’ve been ‘compliant’ with treatment). And this will never go away, as long as you live. Managing a long-term condition, particularly one where the healthcare system demands many interactions, is like having a second unpaid job on top of the one you do to pay the bills. What does this mean for the way you deliver care, particularly for people who are living with long-term illness? Firstly, the more doctors can do to understand and relieve those pressures, practising ‘minimally disruptive medicine’ where possible, the better (see ‘Further reading’). Are there ways for us to get the things we need—results, advice—at times and in ways that don’t disrupt the things we love or need to do? Secondly, if we don’t share your priorities when it comes to treatment and self-management, can you find a way to respect that? Ultimately, we are responsible for our own bodies. For example, if I choose a behaviour you believe to be noncompliant, risky, or that you simply disagree with, it is me, not you, who lives with that choice every day. I cannot walk away from it, my illness comes with me. In fact, perfect compliance with a recommended treatment is sometimes impossible in the real world, especially if you are asking someone to do it for the rest of his or her life. When you talk about doctors and patients reaching ‘concordance’ over treatment or practising ‘shared decision-making’, there is still an underlying assumption that at the end of our discussion, we will agree with each other—perhaps most likely, that you as a doctor will get us as patients to agree with you. But not all your patients will agree with you, though, and that is not a terrible thing. We may even prefer to hand some of the decision-making back to you, and that is not a terrible thing either. It’s not your job to make us think like you, or even to make us share your decisions and your enthusiasm for medicine, but we need you to help us live the lives we choose. We are still doing healthcare when you’ve gone home In the traditional patient/doctor model, the doctor is seen as doing the ‘work’, deciding what is wrong and what should be done about it, and the patient is the passive recipient of care. But once that patient is diagnosed with type 1 diabetes, or Crohn’s disease, or Parkinson’s, or thyroid disease, or has chronic pelvic pain, or another condition that changes life on a permanent basis, that model stops being effective. As patients we are having to do our own healthcare work, not just while we wait to get well, not just during working hours, but all the time. In many situations, a carer may also be doing a lot of that work, and their life choices are affected too. My condition is a particularly good example of this. In the last year I had to make over 2000 decisions about the dosage and timing of the dangerous drug I need to keep alive, and then followed up those decisions with action. I have also made at least another 2000 decisions about monitoring the effects of that drug, as well as monitoring other related aspects of my health.

Some of those actions have been in the middle of the night, in the middle of important workplace meetings, on planes and trains and buses; doctors were not present for any one of those. On 2 days out of 365, doctors helped me discuss a few of my decisions and supported me to get further tests that I needed. I am very glad of their help, but however good my doctors are, their work is only a part of the story of my illness. People like me are making healthcare decisions when you are not there, because we have to (Fig. 1.3.3). What does that mean for the way you work with patients? Well, a good model might be to see us, particularly those with long-term conditions, as full-time colleagues on a job where you are only working part-time. Please understand that we are in fact the primary caregivers, part of the healthcare team, in fact we are leading that team most of the time. We will know less than you about particular topics and may need your help in new or difficult situations, but that is true of your coworkers too. We will certainly know more than you about the way our disease affects Discussion with doctors Decisions made alone (99.8% of time) Ad-hoc adjustments Healthcare access work Decisions about dose/timing Medication delivery Self-monitoring Nutrition management Fig. 1.3.3 Hours of healthcare work done in a year. Data approximated from the author’s personal experience, diaries, and medical data in a typical year of living with a complex chronic condition.

us and how feasible it is to incorporate your suggestions into our lives. After years with a chronic illness, we may well know a great deal more of the biomedical facts about our condition than you do. Just as you would take advice and gain knowledge from a colleague on something you aren’t an expert in, you can take our advice too. If you see us as a full-time worker with local practical knowledge, and yourself as an advisor to our project rather than leader, that may help us work together. And just as you would ensure a good handover of care to the healthcare professional taking over from you at the end of a shift, you also need to ensure good handover of any changes to our care to us. This means explaining what has changed and why, what needs to happen next, and where we can look for support and training in areas we are not yet familiar with. If you don’t, we can’t do our work safely. We look for information just like you do If you are ill, what do you do? You probably do one or more of the following: 1. Think about what you already know about the possible causes and management of your illness 2. Ask colleagues or friends who might have more information 3. Look information up 4. Make a decision about whether you need to get more formal advice and tests Everyone does a version of this, although how far each of us takes it depends on how scared we are or how difficult it is for us to gather the information. In the past, patients had to be particularly educated or motivated to access medical facts and penetrate doctors’ jargon. Now it is becoming far easier for all of us, if we want to find out how to cope with an illness, to go online to find what we need. For some doctors, that has in the past been seen as a source of annoyance or a threat. When I teach medical students, I often show them social media and online forum discussions between patients, with no doctor moderating the information. It is interesting to watch the students’ unease shift, after spending time on those forums, as they realize that crowd-sourced patient advice is transforming people’s lives for the better. Peer support is particularly valuable for those of us with conditions that need constant work. Often we encourage each other online, share the rationale for our decisions, offer advice and help in the middle of the night, when you cannot be there to advise us. Sometimes, we correct inaccurate advice given by well-meaning health professionals whose knowledge is too general to be helpful. In an era when people can connect so easily with others in similar situations, patient-sourced information (support groups, online forums, crowd-sourced info) is at least as valuable as the information in your textbooks, if not more so (Fig. 1.3.4). Don’t be afraid of it. Learn from it. Don’t be worried if your patient has gone to the internet for more information—isn’t that what you do, if you can’t Fig. 1.3.4 Many patient communities have been set up by and for those living with a particular condition, such as #GBDOC. They are not moderated by the medical profession. Regular tweetchats share information about treatment and technology, as well as offering emotional support.

1.3 What patients wish you understood 13 get it from colleagues and the books around you? And if patients are seeking out more information about their condition, it means they are interested and engaged. What does this mean for the doctor’s role? Again, this means a change in medical thinking: if we know things you don’t know, if patients help each other and seek information in other places than your clinic or surgery, then work with us, add your expertise to ours rather than being threatened by it. Where we can, let’s learn from each other. The future of good care In my work in medical education I have met many clinicians who are already practising these different working relationships with their patients and finding it rewarding. There is no need to be afraid of patients who know more than you, who think differently from you, or who challenge the traditional doctor/patient relationship. For doctors who have learnt to focus purely on diagnosis and treatment, perhaps it is a question of using your knowledge and skills in a slightly different way. Thanks to modern medicine, more people are living with disease rather than dying of it, but that change means that the doctors’ role becomes less healer and curer, and more an advisor and supporter. If I have an acute curable condition, it’s likely that your aims and mine are aligned. We both want the problem to go away. If I have a more complex issue, or a lifetime of living with a condition, I may challenge your ideas of the best outcome: I may need to define my- self as something other than just my disease. I may need to com- promise on your medical goals in order to live the life I want to live. I may disagree with the outcomes you have set for me. I may be doing nearly all the healthcare work my condition demands, and I appreciate it when you notice and respect that, but I do still need you. Let’s work together. Acknowledgements My sincere thanks go to the authors in the BMJ’s What Your Patient Is Thinking series, and to those patients, carers, and doctors who have advised me while writing this chapter. In particular I would like to acknowledge the help of Ruth Bender-Atik, Mary Cheetham, Jo Crocker, Sally Crowe, David Griffiths, Abi McNiven, Rajiv Mehta, Jane Moore, Tessa Richards, Sara Riggare, and Michael Seres for their input and support. FURTHER READING DeBronkart D, Sands D (2013). Let patients help. Create Space Independent Publishing, New Hampshire. Entwistle VA, et al. (2011). How information about other people’s personal experiences can help with healthcare decision-making: a qualitative study. Patient Education and Counseling, 85, e291–8. Greenhalgh T, et al. (2015). Six ‘biases’ against patients and carers in evidence-based medicine. BMC Med, 13, 200. May C, Montori VM, Mair FS (2009). We need minimally disruptive medicine. BMJ, 339, b2803. Miscarriage Association. What women and their partners think student doctors should learn about pregnancy loss. https://www.miscarriageassociation.org.uk/information/for-health-professionals/. Patients Like Me. https://www.patientslikeme.com/ What Your Patient Is Thinking, a monthly BMJ series written by patients and carers, with learning outcomes for healthcare professionals. http://www.bmj.com/specialties/what-your-patient-thinking

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