1.2 A young person’s experience of chronic disease

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ESSENTIALS For as long as I can remember, my life has involved hospital care, both as an inpatient and as an outpatient. I’ve never really thought of myself as having a chronic condition, but I have three of them— haemophilia A, hepatitis C and HIV—and have had innumerable medical interactions. Over the years there have been many changes in my treatments, and although these have been to my benefit I have found that they can be unsettling, as are changes in the medical team looking after me, and some changes in the ways that doctors have tried to communicate with me, a notable example being reluctance to give clear recommendation about the best course of action. What remains constant is the trust and communication you can share with the medical team. The Collins dictionary defines chronic as something continuing for a long time; constantly recurring or (of a disease) developing slowly, or of long duration. I’ve never really thought of myself as having a chronic condition. I recently turned 39 but it never really struck me. I was diagnosed with severe haemophilia A at the age of about 14 months. Later, I remember having hepatitis (when I was older this was confirmed as hepatitis C) and later still, I remember being told I was HIV positive. It wasn’t until recently that these infections have been referred to as chronic conditions and it feels strange writing the words as they seem to add a sense of permanence to my illnesses. For as long as I can remember, my life has involved hospital care, both as an inpatient and as an outpatient, under the care of many different departments of the National Health Service. There have been numerous medical interactions, too many to recount here. However, as time has progressed there have been underlying broader themes that affect the level of care I have received and I think are very relevant to anyone who is receiving ongoing medical care. These themes are Trust and Communication, the cornerstones of relationships. ‘Learning to trust is one of life’s most difficult tasks'—Isaac Watts A trip to the hospital or to see the doctor for a single issue doesn't require an advanced level of trust. A chronic condition requires the patient to develop a bond of trust with their care provider to make decisions that will maintain or, ideally, improve the condition. Vice versa, the care provider, be it doctor or nurse, needs to be able to trust the patient to take on board their advice and be sure any medical plan will be followed, whether it is a set of exercises or a rigid treatment regime. This is a process that occurs over time and, with a chronic condition, time is something that can be afforded. I was diagnosed with haemophilia A as an infant. This was when my family and I were introduced to my first doctors. These were the doctors who explained what haemophilia was, how to treat the con- dition, and how best to manage the condition and its consequences. They taught my mother, and then me, how to infuse factor VIII. These were the doctors who I grew up with. I learnt their manner- isms, I grew accustomed to their tones of voice, and how these would change depending on what they needed to tell me. The trust was solidified by their consistent approach to treatment and, for want of a better word, the safety and assurance they provided. When they re- tired in my early teens, this process had to begin again with new doctors and a change in treatment procedures (something I will touch on later). Not only is trust important, but familiarity also plays a part in the feeling of safety within healthcare. My haemophilia clinic has been in the same place for 39 years. It has had a facelift and been made slightly bigger, but it is still the same place. My HIV clinic was built alongside it. For all my check-ups and appointments I have been going to the same place. For years there were the same staff, med- ical, nursing, clerical; everyone knew my name and who I was. It is like a home from home (I even refer to it as mine without conscious thought). But this familiarity and trust can cause problems for both the patient and medical staff. I have never really liked change. It could be argued that my con- ditions are always there and, to a point, are stable now anyway. Previously they were changeable, be it the development of anti- bodies to factor VIII, a reduction in my CD4 count, or the need to change my HIV medication. There is always the anxiety when I go to the hospital that something might have changed for the worse. Changing doctors and locations immediately makes me uneasy. A prime example would be going to university. I went away to university to study when I was 18. While most freshers were finding their feet with new friends, housemates, and experiences I was also having to meet new doctors, which for me 1.2 A young person's experience of chronic disease Anonymous

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I tried to make my check- up appointments at my usual clinic when I was home, but sometimes this was not always feasible. Also, in my second year it was decided that that I needed to start taking HIV medication. The decision was made by my regular clinic doctor but, due to the regularity of check- ups to monitor me on the new regime, these had to be conducted while at university. I never felt at ease there. I had spent years with my regular doctor and, again, a relationship of trust had been built up. I knew when he was going to tell me good news and bad. This wasn't the case when I was at university. Every dip in CD4, or rise in viral load, or the need to change my regime was a shock. I couldn’t pre-empt how my appointment would go. I no longer had that split second of preparation because I couldn’t read the tone of voice or body language easily. This was not an ideal situation for the doctor, and I believe I came across as defensive or cagey. I didn’t feel I could be open with him, which can only have made his job harder. This affected my care to the point I left it probably longer than I should have done to notify my doctor when I noticed I was having side ef- fects to a new triple therapy regime (one of several during my time at university). Trust is vital for both sides when dealing with chronic conditions. Linked to this is the topic of communication. I’ve already touched on this; my failure to communicate a change in condition and the ability, once a relationship has been established, to communicate without speaking. Over the years, I have noticed the change in the way patients are spoken to. As an inpatient, as a child, I was spoken to softly with a high degree of empathy, everything was explained clearly in plain language. As I got older and moved to an adult ward, I noticed that the language became more clinical. The empathy is not lessened but it is different, almost as if there is an assumption that now you are older you have more ability to cope. But any change in condition, any increase in pain will always be scary, no matter how old you are. As time goes by, medical practices change. I imagine as a healthcare professional this is all part of the ongoing professional development, be it training courses or conferences. New practices, new treatments are taught. As a patient who only sees a doctor/ nurse once in a while, these changes can go unnoticed. However, I generally see one of my doctors/nurses/physiotherapists every 4 months, and I notice differences in protocols, which can be un- settling. Over time one gets used to a certain way of doing things and suddenly things change, with little or no time to adjust to the changes. A prime example is during consultations. It used to be that you were told the treatment options and the clinician would see what you thought about each option and then it would be made clear which option the clinician believed to be best. In some cases, they would decide for you on the best course of action. However, during a consultation for a surgical procedure, protocols seemed to change. All options were outlined and then I was asked ‘What do you want to do?’. It took a lot of questioning to get a suggestion from the doctor about what the best option was likely to be. There is a lot of pressure on the individual, as the patient, to make this deci- sion. I felt once the options were outlined, communication stopped. While one knows how the condition feels and affects your day to day being, the decision for ongoing treatment/surgery cannot be made without medical knowledge and input. The communication of this knowledge, not just what the options are, but what each one means and which would be the most viable option, remains a vital part of the consultation. With a chronic condition the patient stays with the care team for a long time; longer than some of their own personal relationships. I’ve seen young house officers develop into renowned surgeons. I’ve seen doctors and nurses come and go. I’ve seen changes to buildings and to treatments. The only real constant in the life of a patient with a chronic condition is the patient themselves. Everything seems to change around you but you stay, perhaps a little older, a little greyer and, hopefully, with little fluctuation in your condition(s). What re- mains constant is the trust and communication you can share with the medical team.

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