

# CONCLUSION

## CHAPTER SUMMARY

In Chapter 1 we introduced Osler's injunction – "Just listen to your patient, he is telling you the diagnosis". In this conclusion we examine how far Osler is heeded in today's NHS. We assess the value of gathering stories in this way as a contribution to truly listening to patients and their families. We reflect on the extent to which the spirit of the NHS Constitution is being upheld.

From the stories we identify five dimensions of care which is organised around patients: kindness, attentiveness, empowerment, organisational competence and professional competence. We compare these themes with the case and evidence for patient-centred care outlined in Chapter 1. We consider what the stories tell us about the things that patients value, the extent to which these things are put into practice, and what the obstacles are. We reflect on the five themes as the basis for a call to action for improvement. We discuss vital questions of context: in particular, strained funding and workforce shortages in the NHS, and the experiences of COVID-19. Finally we touch on future trends, for example the rise of digital healthcare, and consider the implications for better organising care around patients. After this chapter there is a list of further resources that readers might find useful.

## LISTENING TO PATIENTS

As the compilers of this book, we have been privileged to hear these stories. The experience has been hugely rewarding, and hard. We

sometimes felt strong emotional responses, to the point of tears, not only on a first hearing or reading, but also in the subsequent editing process. Listening required emotional labour.

In reality we had it easy. We had plenty of time and good conditions for listening. We were unencumbered by any associated requirement to take action. It is very different for healthcare professionals who have to listen in busy, hectic and sometimes stressful circumstances. They may lack time, there might be shortages of staff and equipment, they might have to work with poor systems and processes. They might have their own personal difficulties. No wonder cursory questioning and inattentiveness can take place instead of deep listening.

The stories also suggest a deeper problem: that in parts of the NHS there are professional and organisational cultures that don't allow for patients' concerns to be heard. The Cumberlege Review into the safety of certain medicines and medical devices, published in July 2020, just a month after we obtained our last story, makes sobering reading in this regard. This inquiry heard accounts from more than 700 patients, mainly women, who have suffered harm, over decades, as a result of – or compounded by – not being listened to. They tell of severe damage to their unborn babies as a result of being given a pregnancy test drug, or epilepsy medication. Others relate experiences of how the surgical insertion of a vaginal mesh has caused awful pain and incontinence, and turned their lives upside down forever. The chair of the inquiry, Baroness Julia Cumberlege, talks of taking these stories to her grave (IMMD Safety Review, 2020).

## GENERAL THEMES

The picture provided by the Care Quality Commission State of Health Care Report of 2019/20 (CQC, 2020) mentioned in Chapter 1 is consistent with the general tenor of these stories. While most care is good, poor experiences centre on difficulty in access to care, services not working in a joined-up way, people having to “chase” to get the care they need, problems with information and communication, and the caring burden for families.

So this book confirms that there is some way to go before we can say that the principles of the NHS Constitution are being consistently upheld:

The NHS belongs to the people. It is there to improve our health and wellbeing, supporting us to keep mentally and physically well, to get

better when we are ill and, when we cannot fully recover, to stay as well as we can to the end of our lives. It works at the limits of science – bringing the highest levels of human knowledge and skill to save lives and improve health. It touches our lives at times of basic human need, when care and compassion are what matter most. (Department of Health and Social Care, 2021: 1)

The Constitution emphasises the centrality of professional competence, holistic care and kindness. Similar themes emerge from the stories we heard. We have identified five themes which, for us, sum up the difference that well-organised care makes to patients. In accordance with the spirit of this book, we offer them as an insight, a provocation and a call to action, rather than as a definitive judgement. These themes are depicted in figures 8.1 and 8.2 below, as we see them as interconnected, and also as pillars in a house.

The first theme is **kindness**. In the stories, professionals demonstrated kindness when they kept their promises, believed their patients, were generous with their time, rang them at home, conveyed warmth and refused to give up on them and their problems. Kind professionals were “on the side” of our storytellers and not judgemental. They understood the impact of delays in diagnosis and wrong diagnoses. After a difficult time securing care for her mum with early-onset dementia (see Chapter 7, Story 22), **Rabiya** found a physiotherapist who was the epitome of kindness:

*Her name is Lily. I won't forget her name because she was such an amazing person ... [My mum's] in a lot of pain and Lily just got it. I didn't have to justify what I was saying. She just understood. She just listened to me and she said, I understand. I remember she got a walking stick out and it was one of those hospital walking sticks, the grey ones, and my mum looked at it and she said, I'm not having that old woman stick. She was obviously saying it in Bengali to me. I was like, oh, gosh, how can I say to Lily that she doesn't want that stick? I'm really sorry, Lily, I know this is going to sound really childish but her previous stick was black, can she get a black stick? Lily was like, oh, yes ... I completely understand, yes, no worries. If she thinks it's an old woman's stick, that's completely understandable ... and she was just so supportive ... She just went and got the black stick. Mum then was quite happy with that and she responded well, so when Lily was doing some of the exercises with her she was laughing along with Mum, engaging with her. Mum didn't understand what she was saying but Mum could tell from her body language she was being supportive and she just responded really well and it put me at ease as well.*

Casual instances of unkindness and thoughtlessness can be so hurtful:

*Jim had a hernia when he was quite small. We went into the room and the doctor that was going to do it asked if he could bring some students in and I said yes. And then they took Jim's pad off and he said to them, "You've never seen anything like this before and you never will again."* (Lucinda, the mother of **Jim**, Chapter 3, Story 4)

*Eventually I left my GP when he told me that I needed to stop trying to get better because this is obviously what God wants for me.* (**Venetia**, Chapter 4, Story 11)

The second theme is **attentiveness**. Above all, this is about listening and observing closely, and the importance of focussing on the person as well as on the illness. It might include keeping an open mind about diagnosis. The stories indicate the importance of picking up cues, knowing when "labelling" can be helpful, as well as problematic, when patients would prefer a relaxed or a more formal style of communication, and when there might be mixed messages and dissent among family members, particularly when the illness is serious.

Attentiveness underpins an effective therapeutic relationship. In **Kauri's** story in Chapter 7 (Story 25) the family GP understood what was going on and was able to help when tensions in the family were rising as Kauri's father neared his death:

*The GP comes to visit and we have a private conversation with her ... and we tell her how stressful it is. At this point there's lots of family round constantly and it's very difficult to focus on Dad. My other brother isn't helping. He is taking daily calls from my aunt and uncle in the States and insisting that they speak to Dad and waking Dad up when he's asleep. ...*

*The GP said, well, would you like me to go downstairs and talk to them? So... she has a very blunt conversation ... that basically goes along the lines of: these are the last days of his life, this is the time where his immediate family should be spending that valuable time with him ... [They] are going to need a lot of support so the best thing you can do is ... and she points to me and my brother and his wife, support these three and his wife who's upstairs in a very upset state because we don't know what the next few days are going to bring. And actually it was very brave of her to do that, but also because she was the GP, she was independent, she was professional, that message carried authority.*

The third theme is **empowerment**. In Chapter 1 we discussed the contested terminology concerning patient-centred care. The term “empowerment” also has both its supporters and detractors. Some activists and campaigners detect a whiff of paternalism in the notion that a professional should empower them, as in: “I already have power, thank you very much, I don’t need your authority to exert it”. Others react to the individualism embedded in the concept, pointing out that inequalities of power – for example, relating to social class, ethnicity and gender – are structural, requiring collective solutions beyond the realm of the citizen–professional or patient–clinician relationship (McLaughlin, 2015). These considerations can lead to the search for alternative formulations such as “power-sharing”, “working collaboratively” etc. For the purposes of this book, we prefer to stick with the relative elegance and simplicity of “empowerment”, while recognising that the term is not without problems.

There is often a power imbalance between the professional and the patient. In these stories, that appears to be particularly true when the professional is a doctor, rather than a nurse, therapist or emergency staff. A key determinant of the power imbalance is information asymmetry. The clinician has technical knowledge, expertise and practical experience that the patient cannot match. On the other hand, the patient has expertise and knowledge about their life and about living with particular conditions. So who is actually the expert here? As **Joanna** puts it (Chapter 4, Story 9):

*One of the GPs that I've chosen not to see actually has a mug on his top shelf that says, don't confuse my seven years at med school with your Google search. Which ... intelligent people find very offensive. Because, don't confuse your twenty-minute lecture at medical school on my condition with my fifty-seven years of living with it.*

Professional power can be wielded to good effect, as in Kauri’s story above. It also comes to the fore when the patient lacks agency. For example, when the patient is acutely ill, the relationship is necessarily less of a partnership, the professional takes charge and the critical ingredient for the patient is not agency but the trust which they have in the professional, making them feel safe and cared for.

Such cases apart, the normal requirement is for the professional to be sensitive to the patient’s own expertise, intelligence and capacity, and their need for control, and to adapt their style accordingly. This is particularly important for supporting people to take control of their life-long health conditions. Patients use the Internet to find further details

of their conditions and to check the doctor's diagnosis. Many people with long-term conditions find self-help or peer support groups helpful to get more information about their condition, to track whether their experience of care is "normal", and to derive practical and emotional support. Some patients are able to access more formal self-management training and support programmes. The job of the professional is to go with the grain of such self-help efforts and help where they can. For some people there is a natural progression from gaining control of their conditions to becoming involved in supporting improvements in service organisation and delivery. Some of our storytellers had such experiences of patient participation, which have been important routes to personal development and empowerment.

Another important dimension of the power dynamic is that many people's experiences of ill health and of care are overlaid with bias, stigma and exclusion as a result of their condition, ethnicity, age or other characteristics. Some of our stories touch on these issues and the intersections between these areas of discrimination.

The fourth theme is **professional competence**. Many issues concerning technical professional competence – and variations in the clinical quality of care – are beyond the scope of this book. They relate to such matters as training, supervision and clinical governance. On the other hand it is clear from these stories that perceptions of competence are highly important for patients and linked to the other themes of patient-centredness. We were concerned at the frequency with which issues of professional competence arose in the stories, particularly in the context of mental health. **Jonathan**, whose son **Dan** was seriously ill and hospitalised with a physical illness for three weeks (see Chapter 3, Story 3), had some concerns about the clinical competence of the ward nurses, despite their evident compassion:

*I can't think of a nurse who wasn't kind and caring. But they weren't always good at the basics.*

An important strand of professional competence is personal conduct. Patients are highly sensitive to aspects such as reliability and good time management, and the absence of these is keenly felt. These aspects of personal conduct can also be considered part of professionalism – behaviours that are both important in themselves and as signals to patients and families of trustworthiness.

Delays in diagnosis are distressing for patients for obvious reasons. This is a fraught area of care because diagnosis always carries an element of uncertainty, and the diagnosis of rare conditions can be especially

difficult. A misdiagnosis is not always an example of incompetence. GPs are generalists who cannot be expert in all conditions. Nor can they refer every worried patient to a specialist. Indeed, their referral activity is generally highly constrained by local commissioners on cost grounds.

What, therefore, can patients reasonably expect? On the basis of the stories in this book, we have to go back to Osler: listen to your patient because he is telling you the diagnosis. A common theme of some of the stories was the feeling of not being listened to, when the storyteller as the patient knew that something was wrong. Clinicians have to listen and keep an open mind. They must recognise the limits of their expertise and where necessary – and within organisational and system constraints – seek help from other experts. In the light of new information, they have to be willing to acknowledge that an initial diagnosis was wrong and to change their mind. Patients can be surprisingly forgiving of errors made in good faith. It is harder to forgive professional arrogance, stubbornness and defensiveness. Meanwhile, referral systems need to be flexible and should not override clinical judgement.

The final theme is **organisational competence**. The first four themes are very much to do with the abilities and personal qualities of individual healthcare professionals. But individual caregivers work in organisations and systems of care. The extent to which their personal kindness, attentiveness and other qualities can cut through and make a difference is influenced by the wider system: its efficiency, accessibility and responsiveness. In Chapter 3, discussing his son's care over a three-week period in hospital, **Jonathan** (Chapter 3, Story 3) described his confusion about who was in charge:

*It was actually quite difficult to work out what status and authority the different nurses had. I think there is a colour coding in the uniforms. It was never clear. There was never the equivalent of what the consultants did. They would tend to introduce themselves and say, "Hi, I'm a consultant this and I'm a consultant that and my name is so and so." Whereas the nurses would tend to introduce themselves by their first names and say, "Hi, I'm so and so and I'm on duty tonight," but it wasn't always clear how senior they were and how much authority they had. You want to know who's in charge.*

Time is not just in the gift of the individual caregiver but also how systems such as outpatient clinic appointment timetables are constructed. **Shona** who had breast cancer (Chapter 5, Story 15) describes the impact of not being given much time:

*When you go there you've only got five minutes with them. It's only at the beginning when you are diagnosed that they seem to have more time. After two*

*or three years you're just a normal patient and they have to tick the boxes and in five minutes you're out the door.*

These stories frequently tell of examples where the patient, or the carer, needed to “work the system” to coordinate the care when that was not being done by the system. As **Joanna** in Chapter 4 (Story 9) put it:

*I've often said that some aspects of the NHS should be run by Ocado, because it is actually a logistics company.*

Signposting is an important aspect of system competence, and a lack of this can cause patients, and carers in particular, to feel very alone, as expressed by **Sheila** in Chapter 7 (Story 24) while she was struggling to care for her husband with dementia:

*Everything that I've discovered, I've discovered on my own. I didn't know who the gatekeepers were, the signposters. I now am aware that there are useful people but I often discovered them fairly randomly; an article in the local paper offering some sort of carers' support ... coffee meeting, for instance ... which I attended and then found there were other resources that I could access via a very efficient carers' forum. It's all been really random.*

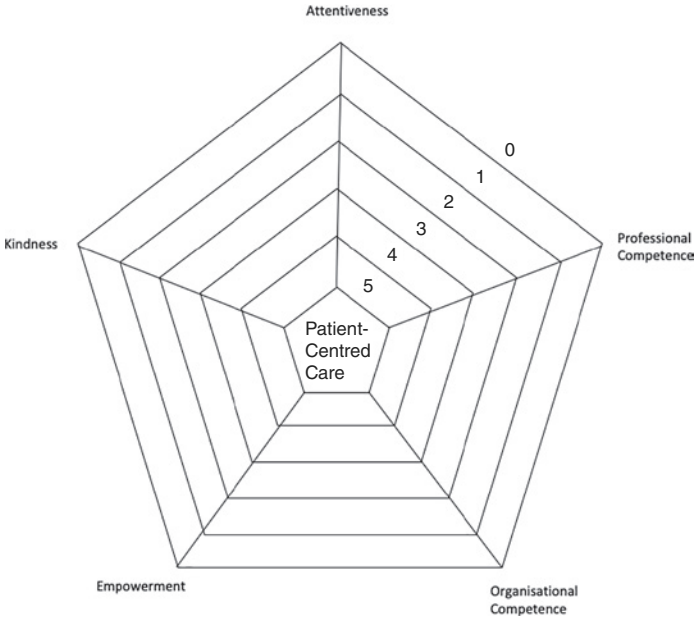
Connected with signposting, fragmentation appears all too common, though it is not universal. Where care is well integrated, it makes a huge difference to patients and to their carers. GPs are well placed to be coordinators but don't appear always to rise to this task. This may reflect the limited capacity of primary care services, which have experienced big rises in demand in recent years, without the substantial funding increases that have gone into the hospital sector.

Organisational competence also includes providing, where possible, continuity of care to individuals. The service needs to be especially alert to the challenges faced by people with rare conditions, because many clinicians haven't come across their condition before. **Rabiya's** account in Chapter 7 (Story 22) also underlines the challenge of providing services that accord with principles of equality, diversity and inclusion.

Figure 8.1 is an aid to consider the interconnectedness of these dimensions of patient-centred care. The stories suggest the importance of these linkages:

*It's the clinical competence along with the compassion, and one without the other doesn't work – it has to be both together. And I think that's what is wrong with a lot of healthcare: people can be very proficient at one or the other and it's those two together. (**Cathy**, Chapter 2, Story 1)*

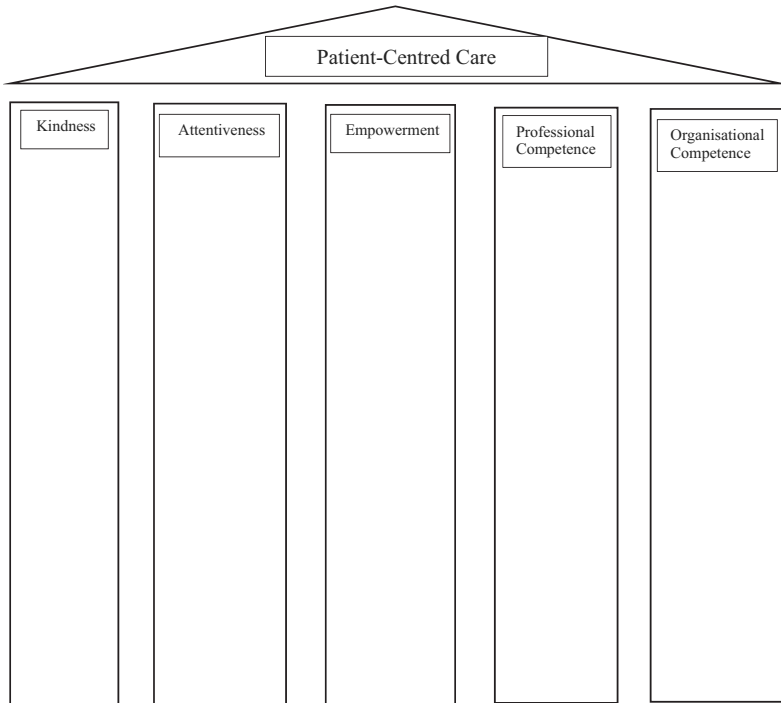




**Figure 8.1** How well is the care organised around the patient?  
 5 = Excellent, 4 = Very Good, 3 = Good, 2 = Fair, 1 = Poor, 0 = Very Poor

The figure can be helpful for those of you who want to take a closer look at one or more of the stories in this book to analyse what is really going on. You can plot how well the care is organised along the five dimensions. Are there links between them? How hard is it to offer kindness in the absence of organisational competence, for example? For healthcare professionals and managers, the figure could also be helpful as a tool to reflect on patient stories that you yourselves seek out or have otherwise heard about – perhaps when responding to a complaint or a compliment, or participating in Schwartz rounds (opportunities for staff, from all disciplines, to come together in a safe space, to share experiences of caring for patients and the associated learning).

In a different way of organising the main themes, Figure 8.2 depicts them as five pillars which we suggest symbolise the solid foundations of care that is well organised around patients. We have deliberately left the pillars blank so that readers of these stories can themselves attribute adjectives that relate to the themes.



**Figure 8.2** The five pillars of well-organised care around patients

## IMPACT AND LEARNING

This book will have different meanings and impacts for different groups of readers. We hope that it will have broad relevance. For the general reader, we hope that the stories will offer new and useful insights. You may find some of the stories uplifting and others unexpectedly shocking or distressing, as they show the NHS at its very best, and also when it falls significantly short. The book is in not a “how-to” guide for navigating the complexities of the NHS, but the stories might help you think back on some past personal experiences and on how you might approach the NHS differently in future, in view of some its flaws illustrated by these stories. If you are a patient or carer currently “battling” with the system, we hope you derive some hope and encouragement from these stories.

For voluntary organisations, disease-specific charities and support groups, there is much here to pump up your tyres. The stories show

the valuable complementary role of the voluntary sector in terms of providing information and peer support, and pointers for how closer working with the statutory healthcare organisations could be beneficial.

For politicians, policymakers and commentators, the book is a sharp reminder of how far the NHS has to go in order to make the values of the NHS Constitution a consistent day-in day-out reality. Policies, programmes, workforce strategies and funding arrangements need to do better to produce care that is consistently well organised around patients. As we enter the fourth industrial revolution, 5G and post-COVID-19 era, there is an opportunity to deconstruct and reconstruct services in a different way (see below).

For NHS leaders and managers, some of the stories will make for uncomfortable reading. To what extent could patients in your own hospital or community service be experiencing the kind of lack of attention described in some of these accounts? It is understandably easy to react defensively to evidence of poor care. This was all about workforce shortages and funding problems, you might say. Or, this sort of thing wouldn't happen on my watch. Others may see this as an opportunity to kick-start a fresh conversation with staff and with patients in their care – how are we doing and how can we do better? How can we improve the experience of care for people from Black, Asian and other minority ethnic backgrounds?

For healthcare professionals, especially doctors, at whom some of the harshest criticism has been directed, an immediate defensive reaction to some of the negative experiences described by patients may be natural. How can we provide the care we would like to, with all the deficiencies of the system we are working in? How can we ever measure up to Google? We hope that, going beyond that first instinctive response, reading the stories will yield creative ideas for improving services. In addition to the versatility and creativity shown during the COVID-19 pandemic, clinicians from all disciplines have already demonstrated how versatile and clever they are at this in the quality-improvement work that has been going on quietly in parts of the NHS for over a decade now, often working closely with patients as a starting point.

## FUTURE PROSPECTS

In the Introduction to this book we outlined some of the limitations of our approach. This is a small collection of stories. Many voices are absent. We have not, for example, listened directly to a child, or a patient hospitalised with COVID-19, or a care home resident. All their

stories, and others, deserve to be told, documented and acknowledged in order to understand fully how to organise care around patients. We hope that others will pick up the baton. But we think there is already enough material here, and from other sources, to stimulate a call to action to reset a sense of purpose, priorities and professionalism for patient-centred care. Current circumstances present a unique moment in which this can be done.

COVID-19 has been a “stop” moment for the NHS in 2020 and 2021. On the one hand, normal services have been suspended, and waits for diagnosis and treatment are longer than ever. Many health and care staff have lost their lives as a result of the infection. Staff burnout is a serious concern. There is the potential for vulnerable patients to feel more stranded than ever. **Jonathan’s** story about the emergency care of his acutely ill son **Dan** (Chapter 3, Story 3) is a case in point. Dan spent three weeks on a paediatric ward in a London hospital at the height of the pandemic. His parents reported a sense that, as in wartime, the only nurses left behind on the (non-COVID) hospital ward were very young staff still in training, or a few very senior experienced staff, perhaps too old to be deployed on the COVID-19 frontline.

On the other hand, something has happened in the NHS which is similar to Schumpeter’s notion of creative destruction, derived from economic theory. COVID-19 has prompted instantaneous revolutions in processes from within, simultaneously destroying old practices and creating new ones. Clinicians from all disciplines in GP practices, hospitals and in community services have moved swiftly to telephone or online consultations and to remote prescribing. The days of standard hospital outpatient follow-up appointments of questionable value (for example, as described by **Robert** in Chapter 7, Story 21) may suddenly be over. New hospitals usually take ten years from first design to the day of opening – pop-up hospital wards have been built in a fortnight.

5G offers the opportunity to embed the digitisation of the NHS, a move which has accelerated with the advent of the COVID-19 pandemic. Technology is a cornerstone of the future of healthcare, and the NHS Long Term Plan is predicated on the rise and adoption of digital services and data sharing. 5G will allow diagnoses using artificial intelligence (AI), enable remote monitoring of the millions of people with long-term conditions, and facilitate remote access to specialist consultations and advice.

Designing digitised care systems around the needs of patients rather than around the needs of organisations and professionals will remain a challenge. Those who are at least partially digitally excluded cannot be left behind in this brave new world. Concerns about data security will

have to be addressed. Above all, it will be important to build into the design the right ways of working, with the necessary attitudes and behaviours. However much the technology advances, healthcare will remain a fundamentally human endeavour. Kindness, attentiveness, patient empowerment, professional and organisational competence will all still matter.

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