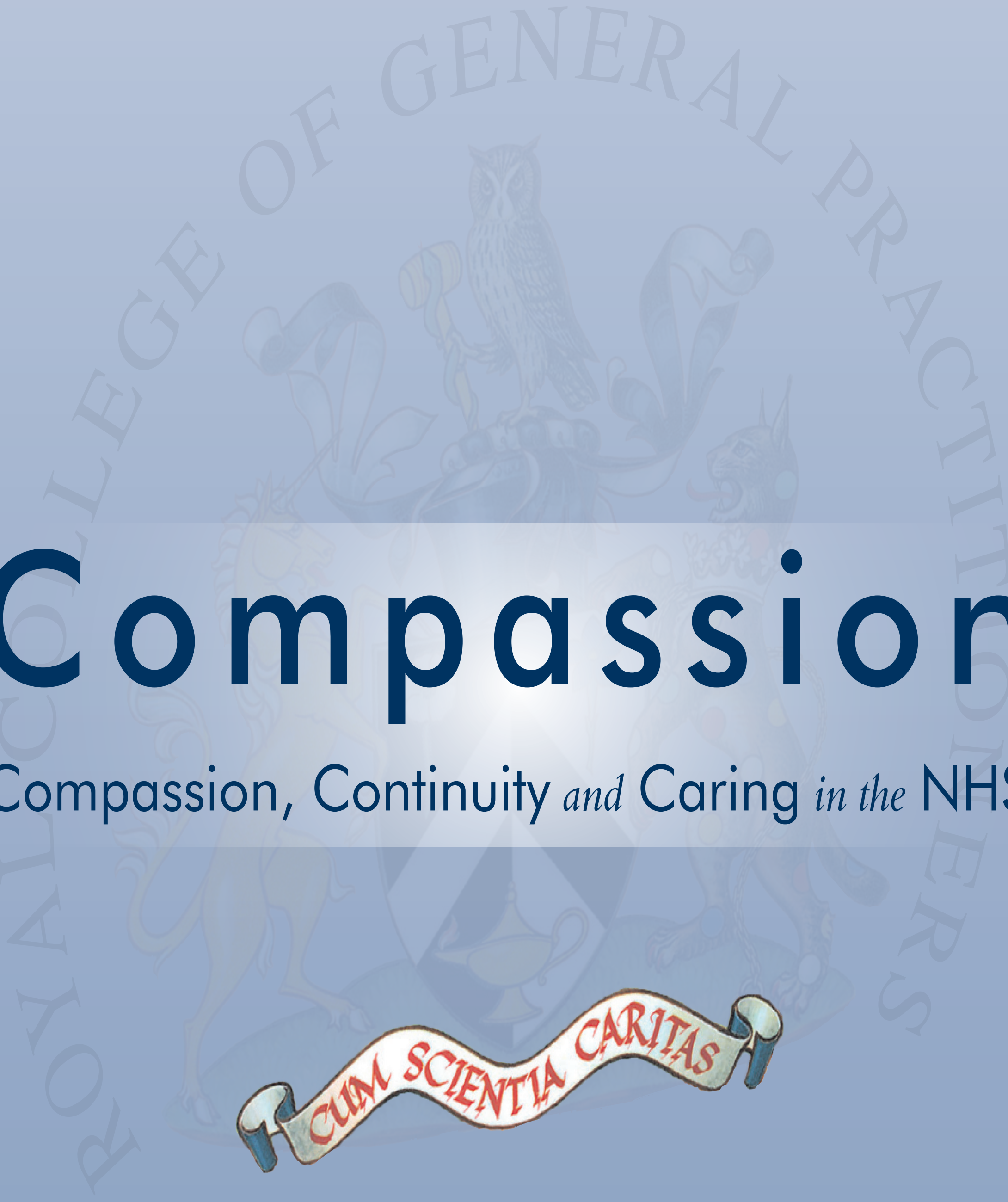

Compassion

Compassion, Continuity *and* Caring *in the* NHS

Rodger Charlton

RCGP
Royal College of
General Practitioners

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The Royal College of General Practitioners was founded in 1952 with this object:

'To encourage, foster and maintain the highest possible standards in general practice and for that purpose to take or join with others in taking steps consistent with the charitable nature of that object which may assist towards the same.'

Among its responsibilities under its Royal Charter the College is entitled to:

'Diffuse information on all matters affecting general practice and issue such publications as may assist the object of the College.'

British Library Cataloguing-in-Publication Data
A catalogue record for this book is available from the British Library

Published by the Royal College of General Practitioners, 2015
30 Euston Square, London NW1 2FB

Designed and typeset by Prepress Projects Ltd, Perth, UK

Printed by Hobbs the Printers

Indexed by Susan Leech

ISBN 978-0-85084-401-6

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FOREWORD 1

This book shouldn't be necessary. Why would anyone in health care need reminding that compassion is central, critical, essential? The humane quality of understanding suffering in others and wanting to do something about it must be one of the most profound drivers for anyone choosing to have a career in medicine – and yet all too often compassion can evaporate like mist in the morning.

Whatever your professional role might be, you are a patient too. As patients or as relatives we all know when care is delivered with compassion and when it is not. I have received care that has been of the highest quality, combining technical competence with great compassion. But I have also been treated with offhand arrogance that has taken my breath away. After leaving a consultation with one doctor who showed not a single microgram of compassion, I turned to my wife and said, 'I'm really frightened now. I don't want to need that man in my life.' Good doctors take away fear. Uncompassionate doctors worsen it. This matters – not just from a human and humane perspective. Confidence and trust produce better outcomes.

So if compassion is so central, why is it not the guaranteed norm in every single encounter with health care? Patients want and deserve to be treated with respect, dignity and compassion. Sometimes they experience care that is impersonally focused on the task, rather than the human being. We need to understand why that is.

I have my own evidence-free hunches, and I have long suspected that lack of continuity is a factor, both in primary and secondary care. Patients quite rightly stay in hospital for a very short time, but the unintended consequence is it is difficult for their doctors ever to get to know them as individuals. You have to be much more skilled to build up a caring relationship in a short space of time. A combination of shift work and rapid patient turnover in hospitals means that the doctor or nurse has no time to learn about the real human in front of them, and to take that learning into their careers.

And in recent years general practice has frequently become focused on access rather than continuity. Ask your non-medical friends who their doctor is and they will say, 'Whoever I can get to see.' All too often there is no real relationship, just a succession of isolated ten-minute snapshots seen by different doctors, rather than the full movie of a life.

On top of this there is the whole issue of our sheer busyness. It is extraordinarily difficult to be compassionate when the pressures on you are overwhelming. Exhaustion can so easily be dehumanising. And even the finest doctor can feel overwhelmed. The more caring the doctor, the more the risk of compassion fatigue. Some might fear

– either consciously or subconsciously – that if they share their patient's pain, they won't be able to bear it. And much of this is linked to the drivers that made us want to join the caring professions in the first place.

So what is to be done? We can start by valuing compassion, and care, and dignity. Everyone with any influence on the healthcare system has to recognise the absolute essential importance of these aspects of care. This isn't to denigrate the technical and the biomedical. It is to recognise the fact that these are synergistic – we absolutely need both.

The NHS's definition of quality now looks at safety, effectiveness and patient experience. The experience of compassion has a profound effect on every patient's experience of care. By focusing on this vital aspect of care, this book is reminding us of what matters. There is an old prayer that says 'Rekindle our compassion'. This book will do exactly that.

Prof. David Haslam CBE
Chair, National Institute for Health and Care Excellence, Past President and
Past Chairman, Royal College of General Practitioners

FOREWORD 2

For many years my local regional hospital had the technically best unit to which to refer a woman with a breast lump. However, I would always explain that the lead surgeon, who they would usually see, had no interpersonal skills. He was brusque, even rude, in his consultations. I would urge each woman to come back to me soon after being seen in the clinic for interpretation and discussion.

A few years ago a Primary Care Trust engaged me to review some of their more problematic GPs. One of these was a serious underperformer clinically, but his patient group loved him and described him as a true friend in their distress.

These two examples illustrate for me the importance of both technical competency and caring ('*Cum scientia caritas*') and how neither can be valuable without the other. Patients tend to take the competency of their doctor for granted – and hopefully that confidence is increasingly justified.

They are however much better able to assess their doctor's interpersonal skills. They are co-producers of the relationship that lies at the heart of general practice, developed over time. The outcome of this is mutual trust and respect.

A key catalyst for this trust and respect comes from a skilled use of empathy and compassion. Sharing an understanding of feelings and circumstance, whether by conjecture or shared experience, is extremely powerful in developing mutual affinity.

Compassion is often instinctive, coming from concern for a fellow human being. Sometimes it has a learnt or practised aspect as can be the case with empathy. Whatever its roots, compassion is at the heart of good general practice, helping to create the long-term relationship that we and our patients prize so highly.

This book is a fascinating exploration of the importance of compassion in our clinical work and our lives in general. I commend it to all members of the RCGP.

Prof. Mike Pringle MD PRCGP
President of Council, Royal College of General Practitioners

FOREWORD 3

General practice is facing unprecedented pressures as family doctors try to manage an ageing population and rising numbers of patients against a backdrop of diminishing resources and a severe shortage of GPs. But in the scramble to balance budgets, tick boxes and achieve targets, we must never lose sight of the things that patients value most and which simply cannot be measured.

Kindness and compassion are the fundamentals of good patient care – and none of us working in the NHS must ever underestimate the importance of them. It is a great privilege to be a GP, to work with our patients, with their families, and with local communities. GPs have a unique role in the health service in that we are the only clinicians providing 'whole person' and continuous care for patients: care that considers the needs of the individual rather than treating medical problems in isolation.

The partnership between patient and GP develops over years, often from birth to death, and it gives us the opportunity to do good and to make a real difference to the lives of others. Over 1.3 million patients visit their GP surgery every single day. GPs and their teams are seeing 370m patients a year – 70m more than five years ago. We are also dealing with complex diseases that, even a decade ago, would have been referred automatically to hospital consultants. Yet as patient demand and the complexity of our caseloads has increased, the share of the NHS budget allocated to general practice has fallen and is now at an all-time low of just over 8%. As a consequence, we now have many doctors approaching retirement and not enough medical graduates going into general practice to replace them.

GPs go into general practice to care for patients. We listen and our patients share their feelings, their fears and their secrets with us. We must ensure that we have the support, time and resources necessary to focus our attention on what matters most.

General practice is the cornerstone of the health service and strong general practice enables the rest of the NHS to flourish. If properly funded and supported, general practice could provide the solution to so many of the problems currently besetting the health service. We can deliver more services in the communities where patients live and where they want to be treated, given the choice. With more GPs, we can deliver more appointments for our patients, give more time to those who need it – and demonstrate by example that kindness and compassion occupy their rightful place at the heart of the NHS.

Prof. Maureen Baker CBE DM FRCGP
Chair of Council, Royal College of General Practitioners

PREFACE

This book is an anthology of essays written by those who hold passionately that compassion is the central tenet of being a doctor and so of the consultation. It originally started as a project with the West Midlands Faculty and rapidly evolved to include the whole Royal College of General Practitioners (RCGP) (otherwise referred to as the College in this book). The title was debated regularly, and was originally to be *Compassion, Continuity and Caring* with the motto of the RCGP – '*Cum scientia caritas*' – as its subtitle. This is also the motto of the Royal New Zealand College of General Practitioners and the Royal Australian College of General Practitioners, and it captures the art and science of being a doctor with its definition of 'Scientific skill with loving-kindness'.[1]

Some of the authors in this book refer to Dr G.L. McCulloch (one of the original founders of the College) and his paper where he discusses in considerable detail the College motto. I assumed it would be possible to find out more about this GP, who it transpires also authored a book on physiology.[2] However, following careful research, little information remains about this man and his important work for the College. Others have defined *caritas* (and so compassion) as not meaning charity, but rather 'tender loving care'.[3] And, unlike science, it is 'unchanging'.[4]

For me, compassion became an abiding theme of this book, and one that will not date. This text is thus likely to become a seminal work of the College and medicine generally. Too often in medicine people try to measure outcomes with patients and forget or do not recognise that a lot of what happens in the consultation is not an exact science. Instead, it is a fine balance between *scientia* and *caritas*.

I have been privileged to learn from many colleagues who have written in this book that compassion is something that cannot be defined and is individual between patients and practitioners; where a practitioner can be one of many carers – both professional and informal. Those who are accountable for outcomes in the NHS such as politicians and managers should remember that, whatever compassion is, it is what matters most to people who are ill.

In my role as a medical teacher and regularly providing feedback to trainees on their consultation skills, I was shocked to hear one trainee say when feeding back to one of his peers, 'You perhaps should have turned on the empathy switch earlier.' Compassion is not something that you can learn or switch on. A definition of compassion that I found apt was provided by my research assistant, Jane Coomber. Jane, a nurse by training, described compassion as time-consuming emotional labour that does not fit well with a fast-moving world. So, when the effort is made in an ever busy and demanding health service, 'Compassion is like the sun, it just shines' (as written in the addendum to Dr Clive Weston's chapter). I commend this book to you. As editor, I have left largely unabridged the many personal views of my fellow authors. This is because they are speaking from the heart about something that is their own interpretation. These views are based on many years of experience and their understanding of their role in and towards the College and its motto, '*Cum scientia caritas*'.

Prof. Rodger Charlton BA MPhil MD FRCGP FRNZCGP

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ACKNOWLEDGEMENTS

I am indebted to everybody who has contributed to this book and to Helen Farrelly, RCGP Publications Manager, who has worked hard behind the scenes to ensure the book came to fruition.

PART I

Patients and the NHS

CHAPTER 1

DEFINING COMPASSION IN THE NEW NHS

Harvey Ward

An account that is based on the personal experiences of NHS health care that he had in 2008 during his wife's end-of-life care.

I was thinking the other day about how I had the good fortune to become the Lay Chair of the Royal College of General Practitioners (RCGP) Patient and Carers Partnership Group (PCPG) in 2012. I realised that I owed it in great part to my wish nearly seven years ago to 'put something back into the NHS' after my wife Patricia decided on the catastrophic day we learned about her incurable lung cancer that she wanted to die at home with her family beside her. I agreed with her immediately, but had no idea if it was even possible. We had recently completed advance directives so there had been some discussion about our respective end-of-life wishes, but her diagnosis came out of the proverbial blue.

The fact that Patricia did die in our home with our three sons, their wives, our 3-month-old granddaughter and her mother present, and the fact that I had been well prepared for what was going to happen, was not only due to my wife's acceptance of her impending death but also the unfailing compassion of the NHS people that we met during her last three months of life.

About a year after Patricia's death I joined a local patient and public involvement group, and became involved in its activities motivated by a wish to ensure that other people could benefit from NHS compassion. I was alerted to a recruitment advertisement for lay members of the then RCGP Patient Partnership Group and soon after I had joined the RCGP in 2011 I realised that it was a very special organisation, unlike anything that I had ever previously encountered.

My working life before I finally retired in 2008 was mainly in public service as a teacher, then a local authority town planner, followed by ten years or so as a further education college lecturer and finally as a carer support worker. Generally these professional roles were focused upon personal advancement and also about dealing with groups of people – pupils and students and local communities. The exception was my intensely personal carer support role when providing regular one-to-one respite sessions for carers of people with Alzheimer's, Parkinson's and Huntington's diseases. The RCGP, on the other hand, being the professional membership body for family doctors in the UK and overseas, is populated by highly qualified professionals who spend their lives focused on worrying about creating health gain for people they do not know. My time as Lay Chair of the PCPG has made me realise that the RCGP's ethical foundation-stone is in fact 'compassion'.

The intimate relationship between 'compassion' and general practice is embodied in the College's '*Cum scientia caritas*' motto. As a lay person with no knowledge of Latin I am indebted to Dr D.L. Crombie, who translated the motto as 'Science with compassion' in his 1972 James Mackenzie Lecture.[1] He explained that the word 'compassion' has a complex meaning incorporating tenderness, loving care and what he described as 'feeling with' another human being. The authors of the 2009 King's Fund report *The Point of Care* define compassion as including 'empathy, respect, a recognition of the uniqueness of another individual and the willingness to enter into a relationship in which not only the knowledge but the intuitions, strengths, and emotions of both the patient and the physician can be fully engaged'.[2]

Dr Margaret McCartney in her book *The Patient Paradox* warns that 'doctors should [not] attempt to be priests or chaplains. Yet the understanding of what illness and disability mean to a person is fundamental to supporting and tailoring medical care to that person.'[3] Atul Gawande underlines an

> unresolved argument about what the function of medicine really is – the simple view is that medicine exists to fight death and disease, and that is, of course, its most basic task. Death is the enemy … but the enemy has superior forces. Eventually it wins.[4]

I believe that Patricia's death was governed and guided by compassion that extended beyond herself to our whole family who, thanks to the NHS personnel we met, were included and welcomed as an essential part of the end-of-life care process. They understood what an incurable, then terminal, cancer diagnosis meant to a frightened family. We learned so much about palliative care from our GP and the oncology consultants, and in my wife's last week or so the palliative care team suggested that we embark upon the Liverpool Care Pathway. The processes involved in completing the various sections of that humane document enhanced every visiting health professional's knowledge of Patricia as a unique individual, about her advance directive and her personal wishes and beliefs.

Some months after Patricia's death I happened to meet one of the district nurses who had visited us several times and she commented that she and all her colleagues saw our family as something special and welcoming. I hope that the following vignettes will show how the compassion shown by members of the multidisciplinary team helped Patricia, myself and our family to cope with her 3-month-long final illness.

We had known our GP, Dr Woods, for over 30 years while we were bringing up our three sons and always respected him for straight talking, expertise and also a willingness to accept that our knowledge might even exceed his from time to time. Our three young sons contracted whooping cough one after the other and by the time that our youngest started he commented to Patricia –'Well, Mrs Ward, you are the expert so if you think that he has got whooping cough I'm sure you are right.'

I must admit though that I would not have described him as 'compassionate' until the week just before Christmas 2007 and thereafter until March 2008. He had been investigating Patricia's concerns about an incessant thirst through a series of inconclusive blood tests, but noted also that she had complained about 'flashing lights' before her eyes and then acute back pain. He arranged for an urgent X-ray at the local community hospital. Three days later Patricia visited the practice for another blood test and on her way out he rushed out of his office asking if she had ever had TB – 'because there is a shadow on your lung which could well be TB or a remnant of an old attack'.

Our immediate reaction was to cancel our usual big family Christmas because of the risk of passing on infection – especially for our first grandchild, born three weeks earlier. We shared a wonderful quiet Christmas – just my wife, myself and our youngest son who had only moved away a week before his mum became ill. We learned two months later from Dr Woods that he had decided to raise the possibility of TB rather than lung cancer. He explained that he thought that the GP's most difficult task was when and how to decide to break bad news. It is always so difficult to decide – shall I tell them today, are they in the right frame of mind or shall I leave it until next time? His thought in late December 2007 was, 'Why spoil their last Christmas?'

In January he started to visit us on alternate Saturday mornings purely to ask how we were coping and to discuss any problems that had arisen. I asked him on the first occasion, 'But isn't Saturday your day off?' He replied, 'Yes, yes, but it gives me a chance to do real doctoring away from the 10-minute consultations.' One important discussion was about our recent subscription to Dignitas in Switzerland prompted by Patricia's extreme pain, which could only be relieved for short periods. He listened carefully to our ideas and described the concept of palliative care. We had never heard of it so he was able to explain that pain control for cancer (Patricia's main desire) was relatively effective through palliative care rather more than for other illnesses like heart failure or COPD.

What was needed was to identify the most appropriate and amenable drug. This turned out to be oxycodone – a slow-release pill taken twice a day with liquid top-up as required. He was kind and compassionate enough later on to brief me on Fridays or Saturdays about the likely acceptable dosages that I could administer without reference to the out-of-hours service.

On other Saturday mornings we discussed Patricia's often very direct and penetrating questions – often about her likely life expectancy. He was able to tell us, two days after a brain tumour had been identified, that her likely life expectancy was less than three months. Patricia was really grateful to him because she valued unambiguous information, however uncomfortable it might seem. Some weeks later Patricia was bedbound but suffering new discomforts in her spine and legs. He offered to refer her for a scan and to consider possible radiotherapy, but readily accepted Patricia's opinion that there was no point in spending her last weeks undergoing fruitless treatment. We then had a long discussion about how doctors feel obliged to offer solutions in order to prolong life at any cost but how relieved he was that Patricia valued quality and not quantity of life. She and I had agreed that when sitting on the steps of the local hospital after learning about her incurable cancer.

Dr Woods referred Patricia immediately to the local respiratory clinic where we met the chest consultant on New Year's Eve. He briefly discussed the shadow on Patricia's X-ray and carried out a bronchoscopy three days later. Scans were organised quickly and we were soon asked to visit the oncology clinic. After an ultrasound kidney scan we were invited into a quiet side room off the main oncology outreach clinic where we met a young oncologist, Dr Faye Lim, and the hospital's Macmillan nurse. We were told sympathetically, calmly but with great clarity that Patricia had an incurable and inoperable lung cancer. The discussion was open with no rush for completion where we learned about chemotherapy and radiotherapy.

We were given the choice whether or not to accept treatment together with useful literature to take away and to let us know next week. Dr Lim made two light-hearted comments about drugs she was going to prescribe, including one she called 'Dynamite' for constipation and the other that we could probably make a fortune selling the unused drugs on Camden Market. Patricia really liked these direct jokes and told everyone about them.

Before the next clinic we were offered a PET scan but Patricia was so nauseous and ill during the weekend that we decided to refuse to attend. At the morning clinic Dr Lim was so concerned about Patricia's sickness that she arranged a brain scan for later the same afternoon. Normally the outreach clinic would close at lunchtime, but this time Dr Lim accompanied us to the scan unit, waited for the results and then, dragging a trolley of files behind her, ushered us into a side room. She told us quietly that a rapidly growing brain tumour had exacerbated Patricia's sickness. She was aware that we had decided against chemotherapy but also that Patricia valued quality of life over quantity.

The tumour would, within a week, take away Patricia's power of speech and her eyesight. The best way to avoid these terrible outcomes was five days of palliative radiotherapy starting the next afternoon at the regional cancer unit. In order to save time she wrote the directions to the cancer unit on the back of an envelope. Again, Patricia was buoyed up by the compassionate and direct care offered by Dr Lim. Next day, Patricia was extremely pleased to find her welcoming Patricia into the first registration session. My wife was prescribed steroids to take over the weekend but by Monday they had made Patricia agitated and shaky.

Once more, we were welcomed by Dr Lim, who immediately reduced the steroid dosages. Thereafter she checked with us every day until the completion of radiotherapy. The compassionate interest and personal involvement by Dr Lim was a great morale booster for Patricia, who was however exhausted after five radiotherapy sessions.

On our return home after the last session, our Macmillan nurse, who shared the direction of the palliative care team with Dr Woods, advised Patricia that she should have a 'duvet weekend', explaining that the exhaustion caused by five days of radiotherapy directed at Patricia's brain was only to be expected. In her subsequent weekly visits she took part in many difficult discussions including Patricia's question about how she would die. Quite accurately, she was told that she would get sleepier and sleepier.

Our friendly and resourceful Macmillan nurse added that it was her opinion that no one really dies until they are no longer talked about or remembered, and she was sure that our family would continue to talk about their mum for years. Even though Patricia and I had always been humanists this concept served to give us both some cheer.

A few weeks later Patricia asked the palliative care team leader to tell me when her death seemed to be imminent as we wanted all the family to be with us at that time. Three weeks before Patricia died our Macmillan nurse strongly recommended that I arrange Patricia's funeral as soon as possible in order to reassure her that her particular wishes (humanist funeral, woodland burial and a cardboard coffin painted by our youngest son) would be honoured. This seemed a daunting task but, just as the nurse had advised, it would have been impossible to arrange it after Patricia had died. In retrospect it seems incredible to me that these arrangements were made in Patricia's bedroom one morning in a discussion with the undertaker over cups of tea!

Carrying out the recommendation reassured my wife and contributed to the 'success' of her humanist funeral that is still talked about with our friends and neighbours. During Patricia's last week the palliative care team leader described the likely pattern of events to me – about the breathing problems and the tell-tale signs but especially how important it is to keep talking to a dying person because hearing is the last sense to go. She suggested certain topics that I might like to consider and be prepared for the last hours to keep talking, 'painting word pictures', and offering constant reassurances. Thanks to all this helpful advice my family was able to sit and listen, and share the experience of my speaking gently about our wonderful narrow-boat holidays during Patricia's last two hours of life.

Compassion is intimately involved with effective health care. Although my examples of compassionate health care are restricted to my wife's end-of-life palliative care I know, from speaking to them, that none of the healthcare professionals included in my story would see themselves as offering exceptional care. I am humbled by the thought that they produce these compassionate acts in their daily working life as a matter of course. They set a fine example for others to follow.

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CHAPTER 2

THE NHS AS THE JEWEL IN THE NATIONAL CROWN?

Helen J. Stokes-Lampard

THE METAPHOR

The nostalgia, pomp and ceremony of the start of the Olympic Games in 2012 served as the perfect foil to the sense of justice and community that the whole games had brought to the UK following the worst period of financial austerity in recent memory. As the lighting dimmed in the stadium the world looked on faintly bemused as hospital beds whirled onto the arena floor and Britons' eyes brimmed with tears of pride at 'our NHS'. The collective sigh of contentment that 'Whatever else we may fail at, my goodness it's good to be British' accompanied a tacit acknowledgement that we do know that our NHS is one of the greatest jewels in our national crown. There was discreet, smug satisfaction in the knowledge that our international cousins would pause and wonder, and that we sleep well at night without worrying how we will fund our next brush with the medical profession.

The concept of 'a jewel in the crown' is a phrase borrowed from another time. In the twenty-first century, genuine crowns live in museums or remain locked securely in glass cases apart from occasional ceremonial occasions; they are not visible in the real world. Gems are things of beauty, rare, admirable and very precious. They are not accessible to the general population and do not serve great practical purpose. Thus the metaphor fails dismally to capture the essence of what the NHS has been, is and could be for the UK. To suggest that its value is based around admiration at a distance is selling it too short, and overstating its beauty – the NHS is so much more and so much less than a jewel in a national crown.

Accountants, management consultants and scientists argue that the NHS needs to be a sleek warship, a no-frills service, pared back, functional, efficient and good, really good, at meeting a pre-specified brief. However, humans are infinitely complex: in addition to multiple physical and functional limitations we are beset by mental fragility and our social constructs, new societies and environment are not conducive to managing the wellbeing of these elements. Thus the 'sleek warship' model of health care, although comparable to a working diamond, like a drill-bit tip, may be exactly right in the setting for acute trauma and medical/surgical emergencies, and may even suffice for early-stage cancer diagnosis and management, but holistic, patient-centred care and the sophistication of the human soul requires so much more from the NHS if we genuinely aspire to provide a service for the wellbeing of our UK population.

The reality

The apparently insoluble dilemma for governments and policy-makers is the tension between scientific and medical advances pushing ever forward, an increasingly ageing and expanding population, and rising population expectations of what the NHS can and should provide. To provide for the wishes of every patient, healthcare professional and vested interest would rapidly lead to bankrupting the UK; rationing of care and services is not a potential threat in the distant future but is the very core of service delivery in the NHS now – it has to be. The multiplicity of guideline and protocol development agencies is a testimony to this. The new NHS contract, implemented in April 2013,[1] was an attempt to allow front-line clinicians to control the allocation and flow of resources. However, political and medical neurosis led to extensive modification and dilution of the bill so that what transpired was a seismic reorganisation but without the authority to make significant and necessary changes that could lead to improvement, and so the cycle continues.

So, can the NHS be legitimately described as a jewel in the national crown? It is certainly viewed that way by some, particularly when viewed through the rose-tinted spectacles of those who have had life-saving treatment or who have benefitted from long-term support from a trusted, respected healthcare professional. An Ipsos MORI poll in 2013 confirmed that the NHS is the UK institution that makes the general population proudest to be British.[2] Indeed the Commonwealth Fund report of 2014 is a stark reminder that, although we may bemoan the failings of the NHS, it is considerably better than many alternatives.[3] So what we have is an NHS that works better than other systems. However, all jewels benefit from regular cleaning and occasionally re-setting the gems to fit current requirements and future demands. Perhaps it is time to clean up our NHS and look afresh at the potential it contains.

When patients consult their GP with new concerns we know that their assortment of organic problems is invariably overlaid with their unique social and psychological dimensions. The complexity of real life in the twenty-first century means that the lack of trusted communities, lack of spiritual sustenance and lack of family networks have led to a famine of support for the psychological wellbeing of our patients, and that is where a successful NHS may indeed shine as a jewel to the vulnerable who seek help. However, the current GP consultation model no longer fits the needs of patients or their clinicians; to do justice to the holistic needs of our patients takes a remarkable set of skills but also requires sufficient time in which to utilise them appropriately.

The lack of time factored into current NHS systems to deliver the standard of care that most healthcare professionals aspire to deliver is a leading cause of disillusionment and burnout.[4] The ten-minute consultation, which has been standard practice throughout UK general practice since at least the introduction of the Quality and Outcomes Framework (QOF) of 2004, is no longer fit for purpose. In a primary healthcare service that attempts to shoehorn a host of standardised, protocol-driven questions and measurements into a ‘standard appointment’, something will be lost. The patient’s full agenda and the provision of truly patient-centred care may involve areas that the patient had not envisaged (such as incidental findings and the exploration of psychosocial issues).

Applicants for medical school today are as idealistic, aspirational, intelligent and enthusiastic as ever, and the established, but increasingly cynical, profession needs their youth and vision to help retain both the professionalism and compassion that our patients deserve. Generation Y has a lot to teach Generation X and the Baby Boomers about how we work best together; we would do well to listen.[5]

Generational research has demonstrated interesting findings about the workforce. This has relevance to the NHS, which employs healthcare professionals across the full age range. The Baby Boomers, who, by dint of their experience and age, represent the majority of ‘leaders’ in the UK currently, are well suited to this responsibility with overall higher scores on strategic thinking and traditional leadership traits. However, there are notable differences between the generations that will inevitably affect working patterns and relationships in future: Generation X are frequently natural diplomats, educating upwards and innovating downwards. Generations X and Y are more individualist and are better at creative and abstract thinking, and are more socially responsive and people orientated, which is why they have embraced social media opportunities with such enthusiasm. Generation Y are more altruistic and people orientated than their elders. All of these attributes should be nurtured to ensure the NHS thrives and retains its ‘sparkle’.

Note: Baby Boomers 1946–64; Generation X 1965–79; Generation Y 1980–94; Generation Z 1995. …

THE FUTURE

With the release of the latest five-year plan for the NHS in England,[6] it is beholden on all healthcare professionals to think afresh about what models of care are appropriate and fit for the future. We are warned that ‘1000 flowers’ cannot be permitted to bloom, but we are also encouraged to offer up creative solutions to fit the diverse needs of our nation, to manage demand and improve efficiency. In return NHS England has committed to stabilising core funding and upgrading primary care infrastructure.

The workforce crisis in general practice is symptomatic of problems throughout the NHS following a long period of austerity where healthcare budgets have been frozen or risen only marginally at a time of population growth, greater longevity and rising demand from patients. UK PLC may be back ‘in the black’ but the NHS and other public sectors are still being punished financially so the demoralised workforce fears yet more change and many are retiring prematurely or seeking opportunities abroad, with numbers applying for proof of registration prior to emigration from the General Medical Council rising every year since 2010.[7]

The NHS has historically been used as a political plaything. Politicians, keen to leave their mark in the short term between national elections, can’t resist making attempts at ‘improvement’ and so are focused on ‘quick wins’. However, increasingly, high-quality models of care are being demonstrated to require many years to have maximal impact. The Alzira model of health care in Valencia, Spain, has operated since 2003. It provides an integrated and efficient health service with a single provider responsible for the entire range of health care that is delivered to the population. However, this is on the understanding that there would be no political interference and a long-term payback for return on investment.

The Royal College of General Practitioners commissioned an independent inquiry into patient-centred care in the twenty-first century,[8] which confirmed that people with long-term conditions (rather than diseases that can be cured) are the main users of health care and this is predicted to grow considerably. One key finding is that patient care is not delivered consistently, often due to artificial barriers between services structured around a single disease focus rather than the needs of the individual. However, the report is also positive about the future if bold moves are made now to change the focus of our work:[8]

> Care that is holistic, empowering and that recognises the individual's priorities and needs is … particularly vital to those with long term conditions … re-orienting the health and care system around a patient centred approach has the potential not only to improve health outcomes and quality of life … but also to reduce avoidable demand … and thereby help place the NHS on a sustainable financial footing.

An inevitable consequence of change throughout the NHS will be the re-negotiation of the doctor–patient contract. The traditional paternalistic model of the patient giving up control to experts in exchange for medical care and professionalism no longer fits with the burden of illness the NHS is treating. Chronic disease management lends itself to greater patient autonomy, self-care and personal responsibility for health. Thus a new agenda that involves substantial empowerment of the patient needs to be embraced, not feared, by healthcare professionals. An NHS that can evolve to adopt this shift will thrive and survive; an NHS that clings to faded glories is destined for the museum.

SUMMARY

A 'jewel in the national crown' is just a metaphor, imperfect and limited in scope, but it can provide a useful framework around which to consider the current relationship of the NHS with the British public. This is not an ancient set of gems locked behind glass, but working jewels that sparkle when viewed at their best. However, the NHS needs constant attention to ensure that it is fit for purpose in an ever-changing landscape.

It is now time to re-set the gems that comprise the NHS into a modern setting that will provide a service for the future that is run effectively and efficiently. This is a service that will fulfil the needs of patients and that provides the maximum amount of high-quality care for the resources available, and which is constantly learning from itself and other healthcare organisations.

The most distinctive gems, which are the true beauty of our NHS and set it apart from other healthcare services globally, include the continuity of care provided through trusted relationships between patients and their GPs over many years, the provision of highly qualified healthcare professionals throughout the service who understand and work to address the needs of the whole patient, and a universal healthcare service that remains free at the point of clinical need. To remove any of these gems would diminish the whole NHS and tarnish the crown.

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CHAPTER 3

ACCESS AND THE GREAT SOCIOECONOMIC DIVIDE

Dirk Pilat

If you would walk through the streets of Tower Hamlets – a severely deprived borough in East London – on a weekday at around 8 a.m. in the morning, you would frequently come across well-ordered queues of locals waiting patiently in front of the door of their GP practice. Some bring their chairs, some bring their breakfast, some both and make a picnic of it. The anxiety of not getting an appointment with their GP for either themselves or a family member is an incentive for them get up at seven (often after a night shift) and queue for an hour, often just to get that cough checked. If they don't make it to the very beginning of the queue, it is likely that they are being told to try again in a few days, take an appointment in a week or visit their local walk-in centre.

To paraphrase Norman Beale, there is overwhelming evidence that deprivation and good health do not share a duvet, even in 2015,[1] but this is a street scene that is not limited to Tower Hamlets but common across the four nations and likely to get worse.[2] Across the UK access to primary care has deteriorated even though individual GPs are offering more appointments than ever and the majority of us now see 40 to 60 patients per day.[2] Unfortunately the picture that some of our elected representatives and parts of the popular press paint about the efforts of GPs to give their patients access to services differs very much from the view at the coal face. Various political and press entities blame the existing primary care providers for a lackadaisical approach to access or even laziness.[3] It seems GPs just can't win.

DEFINITIONS OF NEED

But what is it that makes access such a vexed issue for patients and GPs? There must be some sort of theoretical framework around the issue that could give the GP on the brink of burnout a leg up to redesign his (or more likely her) appointment system to make the punters happy? It comes as no surprise that the framework around need and demand for health care has already been visited by commentators from social scientists to health economists, and remains controversial. For the social policy scientist Jonathan Bradshaw, there are four separate definitions of need:[4]

- *Nominative Need* – which is the need that the experts (e.g. health policy-makers) decide is the actual, rational need for the services offered
- *Felt Need* – this is what the practice population feels is necessary
- *Expressed Need* – this is what the patients tell you should be provided for them
- *Comparative Need* – this factors in the impact of local characteristics such as deprivation and the other social determinants of health.

The health economists Roy Penchansky and William Thomas unsurprisingly define the variables around access as a market-orientated supply and demand model. They characterise care using five criteria:[5]

- *availability* – the relationship between available services and the volume of patients and their needs
- *accessibility* – the relationship between the location of the point of care and the means of patients to get there (and in 2014 primary care's ability to offer services online and via the phone)
- *accommodation* – the relationship between the operational set-up of the practice and the patient's perception of appropriateness of the provision
- *affordability* – the relationship between the cost of care and the ability of patients to pay for those. At present this is not such a problem for actual health provision in the UK, but transport costs, non-NHS fees and prescription surcharges can significantly limit a patient's ability to access appropriate health care
- *acceptability* – the relationship between a patient's perception of his or her healthcare providers, and – just as important – the healthcare providers' perception of their clients.

INCREASED DEMAND FOR PRIMARY CARE

There is an obvious connection between Bradshaw's explanation of need and Penchansky and Thomas's description of the variables that regulate access: all of them are intricately entangled and not easily separated; all are influenced by a vast range of factors only too familiar to every GP. These factors are the local socioeconomic and ethnic profile, health literacy, health-seeking behaviour and of course the provision of funds from their respective devolved governments. At a time when overall government spending for primary care has been declining since 2005 – hitting its lowest point in 2014[6] – it is unsurprisingly difficult for GPs to offer appropriate access just when the UK is bucking a European trend, delivering an uncharacteristic baby boom with an increase in population of 5 million since 2001. Add to that an increased demand for primary care due to an ageing patient load with an ever increasing range of co-morbidities, we have a perfect storm.

This doesn't mean that GPs aren't trying. The vast majority of primary care doctors joined the profession to follow the mandate of Aneurin Bevan and the Attlee government, which had a strong egalitarian ethos and initiated their radical changes to the UK's healthcare provision to deliver excellent, free health care for patients. And so we are continuing to put in the hours to meet these goals. Even the 2001 NHS Constitution reminds us to provide a comprehensive service to all, based on clinical need.[7]

THE EVER RISING DEMAND

Even though they might be trying their best, GPs are often not in control of the reasons for the ever rising demand in their area. Higher rates of GP consultations are associated with greater deprivation and with lower socioeconomic patient groups[8] but, to make things worse, patients living in the most deprived areas have a higher prevalence of multi-morbidity and longstanding conditions, creating a crisis for the local primary care services.[9] The immediacy of perception of educationally deprived patients puts a strain on appointment systems and greatly increases out-of-hours workload, which is often compounded by patients' lack of access to transport, the internet and a telephone.[10]

Due to the nature of primary care, GPs have few options to change the way their patients access their services. For some years now practices have made attempts to regulate access to appointments via either a GP- or nurse-led telephone triage scheme. Although phone triage can lead to a reduction in face-to-face consultations, it does not reduce overall workload. However, it changes the nature of the workload and does not offer any significant cost reductions.[11] Practices can attempt to divert patients with a limited spectrum of acute, self-limiting conditions to different providers of health care such as community pharmacies, and although this seems to reduce consultations for this limited spectrum of problems it again does not seem to reduce overall workload.[12]

Practices can try to further increase the number of appointments they offer by trimming personal development sessions and reducing consultation time. However, this is likely to be to the detriment of the quality and outcomes of the care delivered, and with negative consequences on perceived job stress by GPs.[13] The kind of desperate decisions made during partnership meetings in the face of overwhelming demand surfaced in 2014. In a rather dramatic gesture, one partnership in Yorkshire and another in Devon wrote to patients suggesting they stay away from the respective practices as, due to overwhelming patient demand, they were not able to provide safe care any more.[14,15]

ANY SOLUTIONS ARE COMPLEX

At this point in the chapter it is now pretty obvious that the issue of access to primary care services in the UK is a multifaceted one. There are no obvious solutions in the current financial climate as it is unlikely that we are going to be able to recruit ourselves out of the crisis. More success is likely to be had by reducing Bradshaw's 'Felt Need' and the health economists' 'acceptability' variables. Negative social determinants of health and lack of functional and critical health literacy are the likely reasons for the increased access rate. They should be the initial starting points in the search for a solution to address inadequate health-seeking behaviour. If central or local government's impact on the improvement of the social determinants of health is not adequate to influence local health-seeking behaviour, GPs are likely left to fend for themselves and change the lives of their patients for the better without an FP-10. This is of course in addition to the positive public health effect that having a GP practice within the vicinity of a neighbourhood already has.[16]

'DIY Health' sessions project

An interesting intervention was initiated by a practice in Tower Hamlets, which, with UCL Partners, started to introduce 'DIY Health' sessions in cooperation with parents who particularly frequently attended. Co-production was the chosen methodology as it gave patients the opportunity to work in partnership with professionals to build resilience in the community through education. Their aim was to place health promotion in a learning environment using participatory action learning techniques as the method of delivery. This ensures the effective transfer of knowledge, skills and capabilities that surround key child health messages to parents. They arranged group sessions to provide an opportunity to practise skills in a safe environment together with other parents. Their attempts at co-production also enabled the development of a shared curriculum that met the needs of both patients and health professionals. After the first cohort of the programme there was a significant increase in access to the Pharmacy First schemes, and parents who had attended the most sessions showed a reduced attendance pattern for GP, out-of-hours and A&E contacts.[17]

Targeting the needs of the local population

Initiatives like this do not have to be limited to child health but can extend to all social determinants of health, with the GP practice a hub for all of the neighbourhood's needs, from educational provision to help with legal, financial and housing issues. Initiatives such as those run by Bromley-by-Bow Centre have demonstrated that they can positively influence all aspects of a community's wellbeing in cooperation with local primary care. It has at its core services that target the needs of the local population as defined by a number of key indicators including local health indicators (on areas related to public health, lifestyle, wellbeing and mental health and clinical health) and indicators relating to the social determinants of health, including poverty, skills, employment, social connections, housing conditions and financial concerns. The Centre's programmes link clinical health as delivered in a primary care practice with a range of provision that supports healthy lifestyles, wellbeing and mental health improvement with a range of programmes that support the improvements in the social determinants of health.[18]

Social prescribing

So, could engagement with the third sector be the solution to our access problems? There is now growing anecdotal evidence that social prescribing in primary care can reduce attendance by giving patients a broader choice of services to engage with.[19] If practices, by starting to use social prescribing, could reduce the frequency of attendances of those patients with the most visits to the practice, a significant amount of appointments would be freed: frequent attenders, defined as those who consult their GP more than 12 times in a year, represent over 15% of the average GP's workload. If practices with access problems could reduce attendance of those frequent attenders by one visit a year, they would achieve a reduction of 1% of their workload,[20] certainly a number to ponder on.

HEALTH-SEEKING BEHAVIOUR – THE FUTURE

In a time when even the Secretary of State for Health would rather take his children to A&E than wait for a GP appointment,[21] it is unlikely that central and local government are going to come to our and our patients' aid and solve the ever growing demand for primary care services. Only by tackling the roots of inappropriate health-seeking behaviour will the pressure on primary care in the UK reduce, and engagement with the local third-sector service providers looks like the most promising solution. Otherwise we will be sooner or later all writing letters to our patients, asking them to stay away if at all possible.

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CHAPTER 4

WHAT'S LOVE GOT TO DO WITH IT?

Learning compassion for medical practice

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DEFINING LOVE

C.S. Lewis, in his book *The Four Loves*,[1] differentiates the love of family and kin, the mutuality of friendship, and the attractions of romantic love, from the fourth love '*agape*'. This is 'the highest level of love known to humanity – a selfless love, a love that is passionately committed to the well-being of the other, because they are human'.

Another word for such a love is compassion:

> made up of two words, 'co' meaning together and 'passion' meaning a strong feeling. And this is what compassion is. When we see someone in distress and we feel their pain as if it were our own, and strive to eliminate or lessen their pain, then this is compassion.[2]

EMPATHY

This resonates strongly with Stewart Mercer's definition of empathy,[3] though he focuses it more on the needs of the clinical encounter:

> Clinical empathy involves an ability to: (a) understand the patient's situation, perspective, and feelings (and their attached meanings); (b) to communicate that understanding and check its accuracy; and (c) to act on that understanding with the patient in a helpful (therapeutic) way.

The construct of empathy is routinely taught to most healthcare professionals, often linked with behavioural skills that allow patients to feel listened to and understood.[4] In most accounts compassion is broader than empathy, often being linked to a more value-driven aspect. Interestingly Mercer's work, which is now more than a decade old, also picks this up in his definition of the moral dimension involved in true empathy:[3]

1 *Emotive* – the ability to subjectively experience and share in another's psychological state or feelings
2 *Moral* – an internal altruistic orientation that motivates the practice of empathy
3 *Cognitive* – the helper's intellectual ability to identify and understand (analyse) another person's feelings and perspective from an objective stance
4 *Behavioural* – ability to convey understanding of another's perspective.

THE ROLE OF MEDICAL TEACHERS

My conclusion is that what we need to do as medical educators is to develop a professional kind of compassionate love, and that what we are trying to achieve is a routine practice where our learners get up to the top of Miller's hierarchy[5] – that they can be truly empathic with their patients, and their response is embedded and *professional* enough not to 'fault out' when the going gets tough. So if we want to help our learners learn to be compassionate, first of all, what do we know about how to do that? And then, what else must we do to enable them to sustain that in practice?

Maslow's hierarchy of needs[6] reminds us that learners will not deliver at this high level without first of all being made safe in their new identity. This means having built their confidence in their own actions through a supportive/caring set of relationships, which enables them to grow and develop to their maximum potential. We also know that they will look to us to act consistently with the goals that we expect them to achieve. So it is unlikely that they will attain a truly empathic state on a consistent level unless they see their trainers and senior colleagues around them delivering on this, and are themselves treated with empathy (indeed, compassion) as they go through their training cycle with its ups and downs.[7]

So what kind of love, or compassion, is needed in an educational relationship? There are probably elements of at least three of the four mentioned earlier. When a young person declares his or her intention to be a doctor, or enters training, we immediately treat this person as 'family' – a special bond engendered by our common identity, part of the same community. That leads to inclusion, attention, encouragement, social networks and the start of them being treated as 'a doctor'.

Then there is a degree of friendship – reciprocal give and take, sharing of experiences, and with some a warmer mutual relationship over time. But the greatest of these I think is *agape*, which is the respectful and unconditional love we have to give to any learner in our student group, our new trainee, our new team member – just because he or she is 'our learner' and we have a duty of care to help this person grow.

This of course is not unconditional love. Just as with patients, we have to set boundaries and challenges, and to make judgements, while still preserving our fundamental aim to nurture them and motivate them to be the best they can be – building self-esteem even if their capacity shows limits over time. This is a hard one, especially where summative judgements are concerned. But it is probably in those most vulnerable, defensive, confused moments when learners most benefit from a genuine compassion that waits and watches, and is persistent in its efforts to move things forward.