

# ***"New Perspectives in Compassion for Tomorrow's Doctors"***

Edited by

**Rodger Charlton MD**

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Front Cover – Photo by Dr Elizabeth Charlton, taken in Mudumalai National Park, India on student elective May 2017

Back Cover – Photo by Dr Elizabeth Charlton, Isle of Jura

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## **PREFACE**

Compassion is a vital part of clinical practice and one that should be revisited regularly.

As part of an initiative with Leicester Medical Students and the LUSUMA (Leicester University Students' Union Medical Association) Autumn 2019 LINK Cycle project this book has evolved. Students interested in writing were asked to submit a potential chapter which could include issues such as;

- Compassion to Patients
- Institutional Compassion to the Workforce
- Compassion between colleagues
- Self-Compassion including mindfulness (looking after oneself)
- Guarding against Dispassion

Chapters invited could be a reflection based on a personal experience or it could be a review of the literature.

The book combines contributions from those in training with new ideas to established and retired clinicians.

A background to the book is the RCGP (Royal College of General Practitioners) motto, "*Cum Scientia Caritas*" – Scientific Care with Loving Kindness. This applies just as much to secondary care as it does to primary care.

This not for profit book was to be made available at the next annual SAPC (*Society of Academic Primary Care*) Conference in Leeds in July 2020, but has sadly was cancelled as a result of the Covid-19 pandemic. In my role with the SAPC as the chair person of the *Special Interest Group on Compassion*, the book was to be given to delegates and this will now happen virtually.

I have edited the book and typeset it for publication so that A5 copies can be printed.

### The 'New Normal'

This book was conceived before the Covid-19 pandemic and what is rapidly being referred to as the 'new normal'. In a personal and reflective moment I have witnessed that compassion might have changed in society as a result and how the pandemic has had a profound influence on us as professionals. One particular way is the change in consulting.

We have moved from almost entirely face-to-face consultations to telephone and sometimes using video or providing photograph, eg, of rashes. The huge difficulty of not being able to see people face-to-face, not being able to examine people, not being able to go and see people in their homes when it's indicated clinically. Sadly, we have no choice as it's not safe for us or patients, so we don't do it except with Personal Protective Equipment (PPE).

This has huge consequences for the frail elderly and dying patients. I used to say that one of the roles of examination was reassurance as on the whole examination is usually normal, but that reassurance comes from what we used to refer to as 'laying on of hands'.

Environments have become more clinical, GPs starting to wear scrubs, being covered in PPE together with strict hygiene procedures before, during and after the consultation. Being entirely clinical in our approach has taken away the previously unmeasurable aspect of our practice and what has made GPs so different from hospital doctors.

I am not saying that is good or bad, but merely new and different and inevitably it will impact on compassion and what was once referred to as 'bedside manner'. As a result of our clothing, the barrier imposed by protective equipment will mean our manner will be different and we need to be aware of both in the short and long term.

### Setting the Scene

I asked two colleagues that I know to set the scene given our current experience with Covid-19. First, Dr Gail Walton, who I worked with as a house officer at the Derbyshire Royal Infirmary nearly 40 years ago. Our self-compassion in those busy days as junior doctors was to treat ourselves mid-morning to an egg roll served by the wonderful and compassionate WRVS volunteers. Second, Dr Anupma Parihar, who like many doctors I have encouraged to be a writer at which she is very accomplished and through writing allows us all to reflect on our practice and ensure we remain compassionate.

### Defining Compassion

In relation to compassion, we cannot measure or define it, nor should we as it means different things to different people, but we must remember that medicine is not an exact science.

Compassion is the most important part of clinical practice and care and I believe our trainees have much to train us in this.

Research has shown that we lose compassionate traits during our training. I know that I have spent a career trying to recognise this and regain my humanity as a medical student where the artificial inhumanity imposed by challenging clinical situations and suffering has had a huge impact.

I have asked each contributor in the book to tell something of themselves and so a short biography will appear at the start of their chapters. And so for my own biography.

### Biography

*First and foremost, I am a GP, although as the result of the pandemic it feels like a rite of passage from the old way of working to what is being called the 'new normal'. I qualified from Birmingham in 1983 and although I became a GP initially in my home town of Derby I was pulled back to my Alma Mater and the lovely village of Hampton-in-Arden, where I am a GP. I have pursued an academic career as my details below show, but I have never stopped being a doctor. In my academic role I frequently say that we have failed as medical teachers if our trainees do not become better and more compassionate doctors than us.*

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## **SETTING THE SCENE**

### **Wisdom, Compassion and the New Normal**

by Dr Gail Walton

*Gail has been a GP in Ilkeston, Derbyshire, for 32 years. She has been a GP appraiser since appraisals began, is a locality lead for appraisal and is a trained GP-S mentor. She works with the RCGP in their Supporting Practices programme and is workforce lead for Derbyshire GP Task Force (an arm of Derbyshire LMC, of which she is an executive director). Her particular interest is in developing collaborative working across the many organisations that provide and input into the provision of general practice.*

‘We live in strange times’ - how many times have you heard that phrase in the last three months?

So what is the nature of ‘strange’?

For me it has been the lack of face to face contact with patients and colleagues as we try to maintain relationships by phone or video or Zoom, with fewer of the non-verbal cues that we so often rely on when words alone are insufficient. The medical school teaching of ‘it’s all in the history’ is true but that look of pain or pallor or ‘just not being right’ is significant too.

Strange too that a telephone consultation is probably no quicker but that in some cases it is much more satisfactory for patient and doctor alike - no travelling, no waiting around, no contact with other people - and for others it is the polar opposite: when, as the patient, you’re lonely and it’s the highlight of your week or for the



doctor you want the ease of comparison with how they were last time you saw them.

Strange that, much as we've followed and understand the measures that have been put in place, we find it difficult to spread out and stay 2 metres apart at coffee time and that whereas we often didn't make it to a coffee break now we want to be together and check in with one another.

Strange that everyone suddenly likes the NHS again and forgive the fact that it's difficult to get an appointment and that waiting times are long.

Strange that everyone wanted to clap and draw rainbows...

...or is it...?

No - it's not strange that we share those human characteristics of needing contact, affirmation and the promise of hope filled days ahead.

## **Setting the Scene – Compassion and the Impact of the Covid-19 Pandemic**

by Dr Anupma Parihar

*Dr Anupma Parihar is a General Practitioner and mother of three. She qualified from St Bartholomews and the Royal London Medical School in 2006 and now practices and lives with her family in North London. She has been working throughout the pandemic period except for whilst unwell with the virus. She loves writing poetry and reflective pieces, mainly on her experiences in medicine and motherhood. Her other loves include cycling, music, hiking, spirituality, meditation, and reading.*

Recently I attended an 'e consultation' training session where we were given digital solutions for dealing with everyday patient concerns. The 'back pains' devoid of red flags would be neatly filtered into the area offering pain relief and exercise and the 'not too bad anxieties' would have their prescription reissued with minimal time and expense. I mentally added this to the list of new skills I had gained over the past three months since the pandemic arose. I was confident in video consults and telephone triaging everything.

I had better connections with 111 and the remote hospital services and I had navigated online teaching from the comfort of my desk. These were all things I would have shied away from previously and not embracing them would have contributed to my inefficiencies and inability to leave work on time so all in all I should have felt a silent victory.

Instead as I watched the course organiser move his cursor through a myriad of digitalised complaints, I deflated inside. I tried to envision the face and tone of voice of the 'back pain'. I thought about those 'cues' he may have easily dropped in my room. The relief on his face when I might have caught his eye and uncovered a more pertinent concern. The 'unusual' persistent skin lump which may have been noted. I thought of the times I cursed myself at 'overrunning' for the sake of one such story and winced, wondering whether I had wished it all away.

The richness of life we have witnessed; old photos, wartime anecdotes, the lines on a face, the whispers in the park, the young man's pride and delirious ladies song. The highlight of my week last week had been an elderly patient's invitation to drive past his prized rosebushes on the way home from work. The pride with which he described their colour, life and scent over the phone was palpable and felt life affirming. His medical concern? Trivial and easily digitalised but the wealth of the exchange and the concept of cultivating beauty in otherwise challenging times had left us both richer.

I relayed my experiences after work to a friend and fellow mum during school pickup and her response was 'I'm not sure I could open up to a computer'. Me too. We stood in a socially distanced queue waiting for our five year olds to emerge, guided by caring teachers cautiously two metres apart.

As this was being written, our country's places of worship are slowly reopening. Our family temple celebrated for its creative outreach requires us to book our ticket slot and not sing our prayers, or stay too long. I tell my children, our new language of prayer must be meditated on before our visit so we express the words of our heart when the doors open for 'our turn'. I see our local businesses display balloons in the doorway, reopened with

staff smiling from a screen. We are all trying to master this new language of distanced care on multiple levels and grow as best we can.

Compassion, that pillar of existence comes to life from wholeheartedly feeling another's struggles and acting to positively help. It is our deepest motivation when our job as physicians and human beings is done well. The means to 'help' in these times is unusual and sometimes foreign to say the least.

'Social distance', 'isolation', 'bubbles', distanced consulting, meeting, celebrations, concerts and the expression 'stay safe' have all become vital phrases our society has learned overnight. I know at the root they are an expression of compassion, perhaps most admirable as they feel counterintuitive.

To care for someone has meant to stay away from them, risking loneliness, isolation and perhaps one's own mental health in the sacrificial act of protecting a loved one. As with the rosebush episode, I have been humbled by examples of the bravery and tolerance of 'shielded' patients in isolation and their innovative ways of maintaining cheer and tolerating their symptoms. This was mainly from a generation who deeply valued and connected with their family doctors, often forging a lifelong bond and for whom the 'laying of hands' and eye contact formed the cornerstone of a doctor's appointment.

There is heartbreak as we hear of these patients and loved ones dying alone and gratitude expressed for those hospital staff who held the phones and relayed the messages. Our tears are shed online over funerals and the loss of physical presence has some days felt unbearable.

When I wrote this in the middle of June, we sat as colleagues in a practice meeting, trying our best to decipher new avenues of care and bridge the gap for those patients who needed more than distance. A glimmer of inspiration came from the reminder that although most things are prohibited, we still have our voice. It is not impossible to 'hear a smile' if that smile is wide enough and we listen out for it.

Just as with the premeditated prayer, our words in consulting can come from a deeper place than mere robotic signposts. Our tones, intelligence and a smile on screen maybe all we have to offer our patients as we actively listen, encourage and guide them but if our hearts and minds follow our words, they have power. It is time to wholeheartedly immerse ourselves into the routes of compassion still open to us for the survival of our spirits and the power to break down the walls of impersonal distance which threaten us.

The future is uncertain but the guiding force seems to come from innovation and discovering the power in the previously commonplace.

Nothing should be taken for granted.

## **Is Phase 1 Preparing us to be the kind of Doctor we want to be?**

by Hannah Brown, second-year medical student at the University of Leicester

*I am from Wellingborough in Northamptonshire. My interests include reading regularly, mostly popular science, but more recently I have delved into a fictional series. I have also started coding which I intend to continue and develop into a skill. Alongside my medical degree I am also learning British Sign language with a view to earning my level one qualification very soon. In the future I hope to write a book to inspire young people to dream big and pursue their ambitions whatever their background.*

In 2017/18, I completed a foundation year\* in medicine that was highly focused on patient centred care and showing empathy. This triggered my interest in how the human side of medicine merges with Medical school teaching. In this chapter, I will be exploring whether Phase 1 teaching\*\* prepares us to not only be competent doctors, but more importantly, the kind of doctor we want to be.

\* The MB ChB with Foundation Year is aimed at students who wish to study Medicine at the University of Leicester, but whose background makes it less likely that they will be able to meet the entry requirements for our standard five-year MB ChB.

\*\*In the early 1900s Abraham Flexner in the USA led to medical education being divided into pre-clinical studies (biomedical sciences) and clinical. At Leicester Medical School these are referred to as Phase 1 and Phase 2 although early clinical experience happens in Phase 1.

## A Personal Reflection

### Foundation Year\*

During the foundation year there was a lot of emphasis on treating the person not the disease. We often discussed empathy and the importance of identifying what matters the most to the patient; exploring their agenda. We were challenged to use this idea in the form of home visits to a patient with a long-term condition. In pairs we travelled to a patient's home and were tasked with not only discussing their various medical problems, but how they felt about them and the treatment they had received. It became clear that good experience or bad, it was the doctor's interpersonal skills not their clinical skills that made an impression.

I witnessed this for myself on a subsequent visit to a dementia ward, where we each had the opportunity to assist in the activity room. There I saw a connection between healthcare staff and their patients with such high levels of patience and understanding, and no hesitation to reach out a hand of support and compassion. This was such a humbling and eye-opening experience that I think would be very valuable to all medical students, not just those that do a foundation year.

### Cadaveric Dissection

It was also during this year that I had my first experience of the dissection room. It was a very surreal experience; one I was excited for but had no real idea of what to expect. Holding a human brain and peeling the skin off someone's chest, even at this early stage, put distance between ourselves and our patients. Enabling us to do things that too much empathy wouldn't allow for, but perhaps also starting the change in the way we show and feel compassion. A developing of emotional intelligence in a totally unique way.

At the start of year 2, dissections became a lot more intense. So far, I have attempted a digital rectal exam and cracked open a skull with mallet and chisel, all to someone whom I couldn't even introduce myself too. Ordinarily I seem to be able to cope quite well with the rather strange and brutal experience of dissection, but the intimate and personal aspect started to bother me.

Stripping this person of all their dignity and what made them a person didn't quite feel okay. Despite the fact we can never find out the identity of our cadaver, I had heard of other students giving them names, so sometimes I try doing the same. Although it can feel quite strange and even silly at first, referring to this naked stranger under a sheet by a name, always reminds me that she is a she - a person who deserves respect. I don't want to allow myself to numb to the experience.

Despite the difficult nature of dissection, it became clear that most of the time this isn't addressed at all. I assume this may be deliberate, to maintain all the focus on the task at hand, preventing any nerves or unease getting in the way. But I have seen a change in my own mindset, on my first visit to the dissection room I was in awe; it was such a remarkable experience. I thought of the person first, now this tends to come secondary to zoning in on the given task. This approach to our cadaver may be affecting our approach to real patients and plays a part in finding the right distance between doctor and patient.

### Simulated Patients

I have seen this idea continue into clinical teaching and consultation skills with both myself and fellow students. If a simulated patient sticks to a medical problem, this is where we are most confident. There is a structure, a system, and we follow it with our professional hat firmly on. But when the patient deviates from this and needs reassurance and understanding, we



hesitate. I myself am guilty of this. Combining medicine with compassion seems to be where we falter, as we look for guidance in our GP tutors, almost as if looking for permission to be compassionate.

It's useful to practise this to find what feels most comfortable for us, every person has their own style and approach to talking to patients. Likewise, each person has a different approach to showing compassion. Working with simulated patients has taught me that everyone also receives compassion differently too, meaning that building a rapport with your patient is key to adjusting your style to fit the individual.

### Real Patients

I recently experienced a situation like this on the ward with a real patient, while taking a history our conversation took a turn. I found myself confronted with a very distressed elderly gentleman in front of me, it was only when I felt myself talking just as "me" not a medical student, that he relaxed and started to open up. It's surprisingly easy to get stuck in the patten of what you have practiced and following a set of steps in your head to try and cover everything. Perhaps this is why medical students are sometimes viewed to be lacking compassion, their focus is on completing a task and collecting information; it is only when this process becomes more second nature that the two merge to form a more natural interaction.

I have considered that compassion may be sometimes viewed from the wrong angle, that it is something almost reserved for very difficult situations clinically or emotionally for the patient. Whereas in reality compassion can start from the moment of meeting, showing engagement, kindness and addressing concerns can go a long way to building trust. Reflecting on this with Phase 1 in mind, we have developed a lot of these skills in a

short time and I regularly see fellow students applying them in practice. I myself have developed confidence interacting with patients, and recognising their ideas, concerns and expectations is something we talk a lot about.

Every few weeks in second year we have the opportunity to practise this on the ward. We meet in small groups with our hospital tutor, watch how they would do a particular skill and ask questions, we then have the opportunity to do the same. It gives us time to apply our knowledge and concepts that we have learnt in lectures to real scenarios.

### Self-Compassion

During first year we were introduced to the idea of mindfulness in the form of a unit called *the Health Enhancement Programme* (HEP). Each week we would meet in a small group and discuss topics such as mental health, exercise, nutrition and spirituality, and how these interact to affect our overall wellbeing. Mindfully walking and eating were among the activities, making HEP a unit with very mixed reviews, with some students not buying in to its effectiveness.

I also wasn't sure about it at first, meditation and mindfulness did not come naturally to me, however on reflection I think it had an important message. Looking after yourself physically and mentally is essential, particularly when caring for others. We discussed difficult situations we had encountered so far and things we may experience in the future practising as a doctor. Recognising that there are things we find stressful and emotional, and that compassion is something we need to show to ourselves as well as our patients.

To summarise, I think that Phase 1 prepares us well for our work as future doctors. Forming a very intimate relationship with a stranger, allowing them to share very personal things is not an easy feat. Feeling comfortable and able to do this is something we will surely develop over time, and phase one starts this process so that we are able to use what we have learnt in clinical years.

Having said this, whilst experience of dissection, simulated patients and practise on the wards all build our confidence to be a skilled professional, I feel compassion is something that should be addressed further, not just that between doctor and patient, but to ourselves.

# Experience of Compassion and Dispassion as a Phase 1 medical student

by Sujata Dutta

*Sujata is a second-year medical student at the University of Leicester. She came to University after completing her A levels in Manchester. Her hobbies include sewing, rock climbing and playing the flute.*

## Introduction

During the first two years of medical school, the idea of compassion and compassionate care has been introduced to us as students. However, as we have limited patient exposure in the first two years (Phase 1), are we prepared to be compassionate doctors in the future? I reflect on my experiences of compassion during my time so far at university.

## Before medicine

Before applying to medical school, the importance of being compassionate was always highlighted to me. It was evident during my experience volunteering and through observing healthcare professionals that being kind to people and trying to understand what they are going through can make a huge impact on the outcome of any interaction with another person.

During the interview process we were tested on patient communication and demonstrating compassion through role-play stations. It was interesting to try and 'learn' how to be compassionate and come across well in an interview setting.

### Entering medical school

Upon entering Medical School it was clear that there was a big divide between Phases 1 (first 2 years once called pre-clinical) and 2 (clinical) in terms of exposure to patients and style of learning. The first 2 years of the course are very focused on the science of medicine – learning about the human body and things that can go wrong. This can be traced back to the 1910 Report of Abraham Flexner and his recommendation of a biomedical model of teaching “*to support the scientific focus at its core*”. The clinical phase of the course was to enable doctors to have “*the vital link between the practicing physician and the basic scientist.*”(1)

Whilst this is extremely important for understanding disease processes, does it make you forget what you are learning everything for?

### Factors enhancing compassion

Within the first month of university we had a two week Very Early Clinical Experience (VECE) placement – one week in a primary care setting and one week in a hospital. This was perhaps a way of giving us a ‘flavour’ of what life working as a doctor is like. I enjoyed seeing how doctors and other healthcare professionals interact with patients, particularly how small acts of kindness can put a smile on the face of someone who is in pain.

Having not begun the course yet, my knowledge of medicine was limited to what I had learnt in school which meant a lot of the things I saw and heard about during these weeks were beyond my understanding. In a way the only thing I could truly understand was the compassion I saw, and this was the main thing I had to offer whilst on these placements.

In hindsight, there was something very nice about talking to patients without a particular agenda or list of questions to ask,

simply to have a chat with someone and try in some way to make them feel better - not through medical knowledge or treatments but just through basic human kindness.

As I progressed through the first year of medical school, I began the 'Compassionate Holistic Diagnostic Detective (CHDD)' component of the course. I started to learn skills and techniques that doctors use to communicate with patients – how to take a good history, how to make a differential diagnosis and so on. It was interesting being taught about approaching difficult and sensitive topics with patients and how being approachable and putting people at ease can make a huge difference in how comfortable a person feels to open up to you about personal issues. As part of this course, our Belbin group met with a patient who shared their story with us and we then continued to communicate with our patient through an online platform called 'Patients Know Best'.(2)

I found it interesting to compare how different it is taking to someone in person versus via a screen and it made me realise how crucial non-verbal interactions are when demonstrating compassion. For example, you can see when a patient is upset or perhaps embarrassed by information that they are revealing to you and can interact appropriately. As a group, we often found it difficult to respond to sensitive messages without appearing 'cold' or 'blunt' whilst also being mindful to not come across as patronising.

This led to a lot of over thinking amongst ourselves and a conversation that whilst very informative, felt somewhat unnatural. In contrast, when we met with our patient again, we were able to talk much more fluently and this for myself at least felt much more comfortable as I was able to see the body language and hear the

tone of voice of what was being said to me, which made it easier to respond appropriately.

This experience also brought to light to me the fact that we all demonstrate compassion in different ways which was possibly why it was difficult to agree on the best way to respond as a group. Maybe in situations like these, there is no one best way to respond.

Despite some difficulty communicating with our patients through this platform, it did allow us to gain some insight into a patient's life in a way that would not have been logistically possible to have face-to-face, within the first 2 years of medical school. We were able to gain an insight into what it is like for patients to live with long term conditions and some of the challenges they face and what they do to overcome them. It encouraged us to think more openly about different conditions and how patients are able to adapt their lifestyle in order to take part in activities that many of us did not think was possible.

Understanding our patient's daily life and what was important to them meant we were able to see how their condition impacted them. The experience of hearing about a healthcare journey from a patient's point of view made us more aware of the impact of compassionate doctors and carers on the happiness of someone who is suffering.

### Factors discouraging compassion

Having reached halfway through my first year, I was faced with a daunting prospect – my first exam results in university. For many of us we had been used to doing very well at school and all of us had worked extremely hard to secure our place at medical school.

Yet most of us had never come across the idea of deciles before – being ranked against your peers based on exam results.

This brought with it an element of comparison that I had not experienced and many of us were not very compassionate towards ourselves at this time. Although working towards perfection can be motivating and the process of continuous personal development is vital, does our unwillingness to accept lack of perfection within ourselves make us less accepting of imperfection in others? If so, does this have an impact on our compassion towards other people?

The fact that our academic results were the only thing that ‘count’ made it easy to lose sight of the bigger picture and fixate on studying as much as possible at the expense of taking time for ourselves and resting. It was difficult to accept that we would no longer be able to learn everything and that there is no limit to the amount you can read in such a vast subject.

Perfectionism is a trait that is shared by medical students and it pushes us to always strive to be the best. However, this can become detrimental and there comes a point where we have to accept that we have done all that we can do. Perhaps it is easier to be compassionate towards others than towards ourselves. With expectations to be perfect are the expectations of others to not make mistakes, bearing in mind that doctors are human.

### Progressing Into Second Year

During our second year of Medical School, we were exposed to a different environment and style of learning through our first hospital placement. Whilst I had observed interactions in hospitals before during work experience and VECE as mentioned before, this was the first time I was there as a ‘proper’ medical student. It



was an excellent opportunity to practice skills we had learnt at university such as history taking and examination.

However, it soon became apparent to that there are many more factors to consider when talking to a patient compared to when practicing with a colleague. Each patient had their own personal situations with regards to their conditions and I had to be mindful to address sensitive topics carefully. It was challenging, especially at first, to demonstrate compassion by listening to patients' concerns and responding appropriately whilst also trying to run through a mental checklist of everything I needed to ask to ensure I have gained a full picture of their clinical condition.

Prior to this, these two elements had been somewhat separated. For example, I had practiced having difficult conversations and in CHDD as well as taking a general history and listening to a patient's story. I had also learnt the details of many different clinical conditions and specific signs and symptoms that need to be clarified to distinguish between them. However, combining these two things was a new skill that I began to develop throughout clinical placements.

Another element of clinical placements that relates to compassion was the examination of patients that were in pain. My colleagues and I often struggled when practicing examination when what we were doing could be uncomfortable for the patient. This led to an interesting discussion amongst ourselves regarding how as second year medical students, we are not contributing to the care of these patients. Therefore it felt as though we were not being compassionate by causing them discomfort, whereas the doctors that are caring for the patient are conducting these examinations to aid their treatment and hence are demonstrating compassion in that sense. ,

As a group, we were assigned to a doctor for our six clinical placements. This was my first experience of being taught in a hospital and I found it interesting how different it was compared to university-based teaching. An important part of our course at Leicester is the group work component which involves working through cases based on the information given to us in lectures. Whilst this is hugely beneficial for putting our learning into context, it involves discussing answers with colleagues, looking up information and writing down an answer.

In contrast to this, whilst on placement we had to respond to our patient in real time by asking the appropriate questions to aid our understanding of their condition and other problems that they are experiencing. The approach was much more patient-centred and really brought to light how two patients may have the same condition but are so different in many ways and therefore how important it is to consider patients as a whole and actively thinking about what is going on rather than simply following a checklist of questions that I need the answer to.

Our doctor's advice on how they handle particular situations was extremely useful and allowed me to gain a deeper understanding of all the different factors that need to be taken into account. Furthermore, talking to patients directly and hearing their stories gave me a much greater appreciation of the effects that certain conditions have on all aspects of people's lives and I think these experiences will stick with me for much longer compared to a case in a group work session.

Overall, these hospital placements were a very helpful and positive experience despite the challenges we faced. It brought the science I have been learning back into context and was a reminder of why I had chosen to study medicine in the first place – to make a difference in the lives of patients. Listening to each

individual's experiences motivated me to go away and learn more about their condition. It also allowed us to take a step back from the specifics of what we were learning in lectures and encouraged us to look at each patient as a person with their own circumstances and to be compassionate when talking to them.

### The Health Enhancement Programme (HEP)

An interesting component of my first year at Leicester Medical School was the Health Enhancement Programme. This programme was made up of lectures and tutorials that focused on a variety of aspects of health as well as teaching us methods to deal with stress and look after ourselves. For example, we learnt about mindfulness, nutrition and exercise as well as exploring cycles of behaviour change. This was a very different focus compared to the rest of our course material at the time which was mainly centred around science and physiology.

It taught us how to be compassionate towards ourselves, especially when studying a demanding course where the step up from school was being felt for many of us. There was also an emphasis on passing these messages onto patients and delivering care that helps them with all aspects of their life, not simply prescribing medication.

### Cadaver Dissection

As a medical student at the University of Leicester, I have experienced something that very few people, and indeed only a fraction of medical students' experience – human cadaveric dissection.

The thought was daunting and strange to begin with and few of us knew what to expect the first time we walked into the dissection.

Over time, this method of learning has become invaluable for us. However, a certain degree of detachment / disconnection with the body as a person is needed in order to be able to engage with it.

### Conclusion

Upon reflection of the question 'Have my experiences of compassion in the early years been enough to prepare me for the clinical years and being a doctor in the future?' It has become clear that there have been aspects that have aimed to prepare me for this and other experiences that have not. I believe I will not truly be able to answer this question until I start studying and working in hospitals and other healthcare settings in the future and perhaps this is a question that I can reflect on again further along the line.

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## **The need for a bit more compassion towards our doctors and its importance within medical education.**

by Emily Jackson

*I am currently a third-year medical student at the University of Leicester, with the aim of eventually becoming a GP. In my spare time, I enjoy going to the gym and socialising with friends. I would like to have ran a half marathon by the time I am 25. I also enjoy travelling – I have set a goal of visiting (where possible) all of the countries in the world by the time I am 50. My favourite place that I have visited so far is definitely Kiruna in the North of Sweden. I volunteer and like helping others: for example I have volunteered at race for life events and with St John Ambulance.*

### **Introduction**

The concept of compassion within medicine is not new. Guidance for prospective medical students often states that good doctors should be empathetic individuals, who are caring and can establish relationships with patients (Medical Schools Council, 2019). Medical schools choose caring students, so that they can nurture and educate them, in order to produce kind and compassionate doctors. For example, at Leicester Medical School, students engage with the online *Patients Know Best* programme, where over a year they digitally communicate with a patient who has a chronic disease (Smith, 2017). This is unique to Leicester and allows pre-clinical medical students to understand a patient's journey, thoughts and feelings. I think that this is an important way of reminding medical students about the compassionate side of medicine, whilst they are being bombarded with the science in lectures.

The Oxford English Dictionary's definition of compassion is '*the feeling or emotion, when a person is moved by the suffering or distress of another, and by the desire to relieve it*'. However, the concept of compassion within medicine should not just be limited to healthcare professionals (HCPs) being compassionate to patients, as is often how the word is perceived. 10-20% of doctors working in the UK will become depressed during their career – this is higher than figures for the general population (Gerada and Jones, 2017). There is evidently a demand for more compassion towards Doctors from both themselves and the working environment.

My understanding of compassion within medicine is the idea of HCPs demonstrating thought and kindness towards patients, colleagues and themselves in order to provide a truly excellent health care service. During this chapter, I shall focus on how the latter part of my definition is becoming more evident in medicine within the UK and why I think this is important to develop as a key component of the medical curriculum.

### Dealing with sad situations in medicine

In my first week of clinical placement, I was placed in a clinic that was predominantly cancer based – I had never really encountered anything like this before and found it a very sad and difficult morning. Serious illness and death are inevitably sad and unfortunately, a day in medicine is likely to feature many examples. As a student, you quickly jump from learning about the pathophysiology of pancreatic cancer and appreciating the sadness of such situations from a far, to suddenly being sat in a consultation room surrounded by the sadness of the patient and their relatives coming to terms with the diagnosis.

I think this is a crucial time in the education of medical students when it comes to compassion. Students may often feel

overwhelmed by the compassion and empathy they feel towards patients. However, it may be that this is the most compassion they will ever feel in their career – it has been found that empathy declines as medical students progress through their education (Mahoney, Sladek and Neild, 2016). This is likely to be due to a combination of factors, but one may be that because a day in medicine features so much sadness, students and professionals alike become numb to it.

Sad situations on placement have made me realise how easy it can be for HCPs to become overwhelmed due to their work – not only are they often dealing with emotional situations, but they are also working in an extremely stressful and overstretched environment. I believe that part of being a medical student is being exposed to sad situations and learning how to not let the associated feelings overcome us and begin to affect our lives outside of medicine. However, we often hear stories about students getting upset in difficult consultations and being questioned by more senior HCPs about how they are going to cope as a Doctor if they find such situations sad.

### Becoming numb to sadness

To me, this sort of story highlights how compassion can often be misinterpreted in medicine and potentially how the Doctor in question may have become numb to sadness. Compassion can often get confused with other terms, such as transference – this is the idea that when patients get sad, the doctor starts to feel sad too (McNally *et al*, 2019). Doctors should care about how patients are feeling – they should be able to acknowledge a sad situation and want to stop a patient suffering, as this is ultimately the basis of their job. In my first few weeks of placement I noticed this as a bit of a dilemma: if Doctors start to ignore the sadness of situations, how are they expected to demonstrate compassion towards their patients? However, if a Doctor takes on the worries

and struggles with every patient they see, how are they supposed to cope?

### Viewing patients through a pane of glass

Someone once described how to overcome this dilemma to me in the form of a nice analogy: as doctors, we should view all patients through a pane of glass – we should be able to see their troubles etc, but we should be able to keep ourselves separate from the troubles, almost as if the glass is protecting us. I think this concept is extremely important and should be emphasised to students and HCPs alike – it is important that students learn to acknowledge their emotions and deal with it, rather than let them build up, or worse try to stop feel anything at all towards sad situations. By approaching sad situations in this way, HCPs can ensure that they show compassion to themselves, whilst crucially, still maintaining compassion towards their patients.

An example of this is the use of *Schwartz Rounds* with medical students at University College London Medical School. Schwartz Rounds are a group discussion with different health care professionals, where participants discuss social and emotional issues that arise with care. When students were questioned regarding this scheme, they said things such as; *“It made me realise that the emotions and feelings I have encountered over the past year are also experienced by top consultants, doctors and nurses”* (Barker, Cornwell and Gishen, 2016). This demonstrates how important it is to educate students that it is normal to feel emotions as a HCP.

### Overwhelming emotions

Many patients we encounter are dealing with some of the most difficult challenges and times of their lives – and others the happiest. I think a big part of learning how to become a doctor is learning how to deal with the often-overwhelming emotions of



patients. It is so important to show kindness and compassion to these patients as they suffer, rant or jump for joy. But it is equally important that we show the same amount of compassion to ourselves. A doctor that can switch off once the patient walks out of the room will perform much better than a drowning one – and I am sure patients wouldn't ask for anything more.

### How to improve surviving as a doctor

I think that being a doctor is an amazing job, you get to help people and do something you are really interested in at the same time. However, the working conditions are not always great. For example, I have frequently witnessed newly qualified FY1 (Foundation Year 1) doctors on call responsible for up to 50 patients, running around almost frantic because they have so much to do. With increasing strain on the NHS, doctors are often working longer hours with increasing scrutiny. Therefore, it may not be surprising that a study into burnout in UK doctors found that 31–54.3% are emotionally exhausted (Imo, 2017). Doctors are expected to be almost super-human, but they clearly aren't coping.

Low resilience in doctors has been associated with a higher chance of burnout (McCain *et al*, 2017). Therefore, by teaching doctors to become more resilient and teach them this via self-compassion, doctors may be able to cope better with their jobs. For example, at Leicester Medical School, students are enrolled in the *Health Enhancement Programme* (HEP) from the first semester of first year. HEP involves students learning about the importance of things such as sleep, diet and exercise on our health and wellbeing. The programme also introduces students to the concept and practice of mindfulness and the importance of taking some time out for ourselves.

As a student who has taken part in HEP, I found the most useful part of the programme was the mindfulness workshops. This not only teaches us about the principles, but also how to practice it; I think this is important as it can provide us with the skills to take a minute away from the busyness of our thoughts. Student feedback on this programme at Leicester has found a positive correlation between students engaging in mindfulness and their subsequent indicators of wellbeing, such as mood and ability to relax (Hales, 2018). Evidently, introducing self-compassion education into the medical curriculum may provide students and doctors with the skills to cope with the stresses of work better.

However, for programmes such as HEP to be successful, the students and HCPs taking part need to engage with the programme and it is up to the individual to actually use the skills learnt and show themselves self-compassion when required. Unfortunately, a qualitative study into GPs' opinions on resilience training found that the GPs who are most likely to need such training are the least likely to take part and actively engage in the training, due to stress and busy working environments (Cheshire, Hughes *et al*, 2017). Therefore, this provides challenges as to how to effectively provide this training to busy HCPs.

This highlights how important teaching the skill early in medical school is, so that students can hopefully be prepared before the need for self-compassion is present. Furthermore, by teaching medical students' strategies for coping as a doctor, hopefully it will teach them that it is okay to struggle, but that there are ways to deal with it, rather than trying to ignore it out of fear or shame.

### Pastoral Support

In medical schools, students have access to excellent pastoral support units, where they can go to discuss any issues they face. At Leicester University, these are frequently advertised and easily

accessible. I think this is a great example of students actively demonstrating self-compassion, and the university/working environment showing compassion to its students/employees.

However, it was only until reading for this essay that I discovered that there is a *NHS Practitioner Health Programme* (NHS PHP), which was established in 2008 with the aim to tackle mental health problems in Doctors and Dentists. Research into the effectiveness of the programme found that this targeted programme for HCPs improved mental, social and employment aspects of participants wellbeing. For example, 80% of the 255 doctors presenting with substance misuse have since remained abstinent (Gerada, 2017).

I think services like this are crucial to HCPs. Talking about work troubles, life troubles or even any slight inconvenience with someone is surely something helpful. It may be that a specific scheme such as this is necessary to target the complex needs of the mental health of HCPs. However, a qualitative analysis of doctors' experience with the NHS PHP found that the doctors involved in the scheme often left it until problems were severe before seeking help; this was due to a combination of factors, such as difficulty finding help and fears about the consequences of seeking this help (Brooks, Gerada and Chalder, 2017). Furthermore, a study of 959 doctors found that 20% thought that there was no service available for them at work to receive help with their physical or mental health (*BMA - Quarterly survey Q1 2018*. 2018).

There is evidently a demand for schemes like this to show more compassion to our doctors to try and improve the wellbeing of the workforce. But there is also clearly a need for it to be made more acceptable for Doctors to admit that they are human and sometimes, they need a little bit of compassion too.

## Conclusions

The nature of the job and the vigorous application process to get into medicine means that the majority of Doctors are compassionate individuals, who ultimately just want the best for their patients. However, it is clear that Doctors are not very good at directing this compassion towards themselves in a truly challenging working environment. I personally think that by establishing **self-compassion** as a core component of the medical curriculum, Doctors will learn how to better cope with the challenges.

However, for this to truly work, it needs to become more acceptable in medicine for Doctors to seek help and admit they are struggling. Furthermore, GPs asked about coping and reliance have argued that while self-compassion is important, it can only go so far if the working environment and organisational issues within the NHS are not also improved (Cheshire, Ridge *et al*, 2017).

Research has found that the wellbeing of Doctor's is related to higher levels of patient satisfaction (Topakas, Admasachew and Dawson, 2010). Therefore, fundamentally, with a bit more compassion from the working environment and from doctors themselves, the healthcare system will hopefully improve, via a happier, healthier workforce.

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## How Simulation and Clinical Exams in Medical Education Shape Empathy

by Mark Gerlis

*Since the age of seventeen I have worked in healthcare, initially as a Healthcare Assistant. With a keen interest in sport and exercise I decided physiotherapy was for me. I graduated from Cardiff University in 2013 and practised full-time as a physiotherapist for three years spending the majority rotating within the Royal Berkshire NHS Foundation Trust.*

I began studying Medicine at The University of Leicester in 2016 and am currently in my fourth year. I have maintained my physiotherapy registration and continue to work part-time. Overtime I have become more and more aware of the importance of the way healthcare workers communicate with patients and each other. Not only what is said but the way it is said. As a physiotherapist I find it surprising hearing the amount of misunderstanding between patients and doctors and how patients often do not feel listened to.

As I go through my training, I continue to have an interest in communication in healthcare, which led me to thinking about how empathy may be shaped by educational processes.

Communicating empathetically is encouraged throughout medical education and is fundamental to being an effective doctor. Medical students and doctors are frequently told the importance of providing holistic care and understanding the patients' experiences, concerns and perspectives. The task-orientated focus of modern medicine and the ever-growing demand on NHS

doctors can make this difficult to achieve. However, do medical educational processes truly facilitate students to be empathetic? This chapter explores whether teaching sessions involving simulated patients and the focus on clinical exams may be shaping empathy in medical students and doctors. The topic is discussed in relation to current literature as well as from my own personal experiences and observations.

### What is Empathy?

Empathy is fundamental to being an effective doctor. Studies suggest it leads to improved patient satisfaction (1,2), greater adherence to therapy (2,3), enhanced doctor-nurse collaboration (4) and better clinical outcomes (5-8). Empathy, however, is difficult to define. In the context of the clinician-patient relationship it can be divided into two dimensions. The first, affective, describes the passive emotional response of one individual to the emotions of another (9,10). The second, cognitive, is the ability of one individual to understand the experiences of another without invoking a personal emotional response (10).

It is worth noting that the complexity of empathy makes it difficult to assess and quantify with the majority of the studies on this topic using self-reported measures where the validity is questionable (11). This is a widely discussed theme in the literature in terms of study limitations with many arguing that empathy should be assessed and measured qualitatively from more than one perspective (12).

### Empathy and Medical Education

Medical education places an emphasis on empathy as a cognitive attribute that involves an understanding of the patients' experiences, concerns and perspectives, combined with a

capacity to communicate this understanding (13). A key focus of undergraduate and postgraduate medical education is to facilitate the development of empathy, often through sessions involving observed consultations with simulated patients (actor playing a patient) with feedback from peers and educators. Observed structured clinical examinations (OSCEs) are then used to assess empathetic communication and behaviours.

In this chapter I will discuss how the empathy of medical students and doctors may be shaped by these educational processes using current literature as well as my own personal experiences and observations as a current medical student, previous physiotherapy student and physiotherapist. There is little physiotherapy or applied health professional literature in relation to communication.

### Benefits of Simulation Sessions

In medical education teaching sessions involving consultation with simulated patients are firmly established. They allow individuals to practise in a protected environment receiving constructive feedback without the risk and pressure associated with real patients. Empirically, students and doctors find sessions useful, particularly for gaining experience discussing sensitive topics such as end of life care (14). Some studies have suggested that cognitive empathy, where patients feel their experiences, concerns and perspectives have been listened to and understood, can be enhanced by communication skills training involving simulated patients (15,16). Communicating and behaving empathetically not only improves examinees empathy scores in OSCE stations but there is a correlation with overall performance and clinical competence (17,18).



### Critical View of Simulation in Relation to Empathy

Hanna and Fins, and Brauner argue that the empathy portrayed in these artificial settings is a learned behaviour where the student is performing for the educator/examiner to meet the requirements of the checklist (19,20). The authors worry that a medical student may, through repetition of simulations, be able to effectively display appropriate superficial communication and behaviours, but they never learn to really relate to patients. Does this matter if the patient perceives they have been heard and understood? The authors raise the concern that if students are pre-occupied on how the educator/examiner is interpreting their performance, the idea of developing genuine, empathetic connections with patients may not be a high priority for their professional development.

Hodges expands on this and suggests that using OSCEs with simulated patients to assess empathetic communication shapes the way students think about interpersonal and communication competence. Thus, individuals are more likely to adopt this checklist mindset of accepted communication and behaviours when practising as a doctor, meaning they are less able to provide holistic care and show genuine empathy (21). There is very little literature relating directly to medical education and clinician empathy, largely due to the complexity and multifactorial nature of empathy. Examples of enablers of empathetic care are positive role models and good relationships between team members, whereas barriers include time pressures, workload, bureaucratic requirements and protocol-driven care with guidelines (22,23)

### Personal Experiences and Observations

From first-hand experience it is clear that OSCEs are necessary and simulated patient sessions can be very useful, however, I can relate to the issues raised by the authors mentioned.

I find it very difficult to act naturally and be truly empathetic when speaking to a simulated patient in these pressured situations. I want to score well, and my mind tends to focus on my performance to make sure I am ticking all the boxes. I have felt in the past when replying *'I'm very sorry to hear that'* when the simulator explains that their mother died recently it has become a reflex and a point scoring opportunity. In addition, there is an ongoing focus on preparing for OSCEs when on clinical placement.

I have been encouraged by doctors on numerous occasions to pretend I am in a clinical exam when conducting an observed subjective or objective assessment. I find this takes away from the authenticity of the situation and I am distracted from truly listening and empathising with the patient. Similarly, in a qualitative study regarding OSCEs many junior doctors reported focusing on addressing the checklist points rather than focusing on conducting an empathetic consultation and an individual described feeling like *'an actor playing a doctor'* (24).

As a physiotherapy student between 2010 and 2013, I was never coached to be empathetic and compassionate to patients, it was simply expected. I feel this allowed me to develop my communication style naturally. I was able to genuinely listen to patients' perspectives and concerns without feeling self-conscious about coming across empathetic.

### Do Simulation Sessions and OSCEs Influence Empathy in Clinical Practice?

While the limitations of artificial teaching and examination settings in relation to empathy are well known, it is widely regarded that real life clinical experiences as a medical student and doctor is where emotional and cognitive empathy is really felt and

developed. However, based on reviewing the literature and my experiences as discussed, the focus of medical education (undergraduate and postgraduate) on simulation and particularly OSCEs does potentially influence empathy in clinical practice. These experiences, despite their artificial nature, are significant in establishing an accepted approach and mindset to patient interactions. More specifically there is an argument that I feel where a checklist mentality and task-orientated communication is encouraged which feeds into the systematic and efficiency culture in western medicine where holistic care may not always be the main focus (25).

Lastly, it is worth thinking about the long-term impact on the doctor.

*'Not every patient can be saved, but his illness may be eased by the way the doctor responds to him-and in responding to him the doctor may save himself'* Anatole Broyard a New York Times literary critic who wrote eloquent chronicles of his illness before he died (26).

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## **Unlikely, Unplanned & Unexpected**

### **A medical student's recollections of compassion in clinical practice**

by Tomini Fashina

*Tomini Fashina is a medical student at the University of Leicester. Throughout her time at medical school, she has engaged with everything the curriculum has to offer viz. student representation, clinical research, sports, student welfare, global health advocacy, peer-teaching initiatives and widening access to medicine. One of her many passions is reflective practice in medical education. She strongly believes that reflection is the core of a compassionate clinical environment and essential for the holistic training of the doctors of tomorrow.*

“Unexpected kindness is the most powerful, least costly, and most underrated agent of human change.”<sup>1</sup>

It took all my effort to hide my surprise. I sat there, at the back of clinic, or the edge of a patient's bed, sometimes in the middle of a hospital ward. Regardless of where I was, time and time again I sat there drenched in concern and buried in the depths of my mind. My parents' voices echoed throughout, *'to whom much is given, much is expected.'* The age-old quote they would chant like a mantra; reminding me to be diligent, excellent and grateful. They have given me a lot, done so much and sacrificed even more. So, it seems only fitting that they set their expectations of me very high. I think people view doctors similarly.

So many years in training; either in a lecture theatre, a library, a clinic or on a ward. Time & resources have been invested to guarantee clinical excellence. This is all to ensure that when presented with a person who has sub-optimal health, the well-

trained doctor can treat them; not just with medicine but with meaning. There is a great expectation that one's doctor should not only be very clever, but also very compassionate. Thus, in light of all the above, the notion of unexpected and unplanned compassion in the pursuit of doctorhood, seems like a paradox. How can a core outcome of our training only manifest in unforeseen moments? I would like to explore a series of moments where compassion was unexpectedly uncovered to answer just that.

Compassion & cancer should be twin sisters. Fraternal. Both polar opposites and exactly alike. Their fighting and friendship is a trade off every day. Inseparable, unbearable and necessary. When receiving the diagnosis of one, we expect the doctor will also give us the other. Compassion encompasses '*suffering together with one another, participation in suffering, fellow-feeling, sympathy*'<sup>2</sup>. I remember being in the back of the cancer clinic, this time I was standing. Hands behind my back, ready and willing to learn – not just from the doctor today, but from the specialist nurse and dietician too. The lesson was 'how to break bad news'.

I quickly realised that in order to break bad news effectively and empathetically, you need to understand the weight of your words. Patients see cancer as infiltration. It is like a spy that has invaded their headquarters. Its sole purpose is to cause alarm, disaster and destruction. It's sphere of influence extends beyond the individual self and permeates into the hearts of their loved ones. Upon realising its presence, their emotions, identity and existence implode upon themselves, weaving into a tangled web of fear and pain. I saw that in order to break bad news with compassion, you need to understand the weight of your words.

Compassion can be a tool, a device used to carefully loosen the tension of the emotional web. The web may not unravel, but it

can soften. It's temporary but necessary. As a team, we diagnosed over 10 patients in one morning. I would have needed a bucket to catch all their tears. As healthcare workers, when we break bad news, we might not always understand the weight of our words. Doctors see cancer as pathology. Almost instantly, our mental algorithm veers down a pathway of operations, medications and radiation. One quickly jumps from 'there is a problem' to 'I need to fix it', without taking time to accept and acknowledge the suffering.<sup>3</sup>

In that clinic, my mind sped down that pathway before I could blink. I imagined it would be comforting to talk about treatment options and point to medicine as an avenue for hope. The doctor, however, was silent. I stood there, and listened to his silence and that of the patient's. It was deafening yet soothing. Unexpectedly, silence was compassion. It gave the patient space to breathe, to worry, to cry and to pray. Silence, like any other form of empathy, was inexpensive yet impactful.

The average person, laymen or medical, would think that during cancer treatment, compassion should be apparent. The very thought of a human being needing drugs, fluids and radiation to 'beat' an indivisible mass in their body should drown our minds with worry, pain and maybe even prayer. Medical students especially, should be empathetic as their read about these treatments in their textbook, let alone when they arrive there on a Monday morning. That seems to be a reasonable expectation. Well, the bone marrow transplant unit was different, in many ways and in none at all. In some ways, it was exactly like any other cancer-related ward – quiet, clean, full of thoughtful and well-meaning healthcare workers and of course, the mixed air of sadness and hope.



I arrived on time and introduced myself to the junior registrar present that day. I was placed on the ward for the morning. I had to be there. I had to learn something, do something, see something. I began to prepare the patients' notes. Autografts, allografts, AML (Acute Myeloid Leukaemia), the works. I studied their histories so intently so I would be prepared when we saw the patient. I thought I was ready, but I was not. We moved through all four patients like wildfire. The doctor was so focused, professional and surprisingly personal.

When we saw the first patient, I was ready to comment on his levels of immunosuppression and his steady improvement seven days after his bone marrow transplant. But the doctor already knew that. She quickly reviewed it, and did not rush, but rather chatted to the patient about the Rugby World Cup. The next three patients were exactly the same. The doctor pointed out the lavenders tattooed on Mr. X's shoulders and asked about his wife's pregnancy. She spoke to Mr. Y about his bright blue pyjamas and then told Mr. Z he had the most 'get-better-soon' cards she's ever seen in a patient's room. I watched her attentively as she treated the patients with both science and support.

When I walked into each patient's room, I thought I knew what to expect. I thought I was prepared. But, I was prepared for a patient on a page – a physical manifestation of a person defined by medical conditions, clinical presentations and cancer therapy. It was both a rude awakening and a breath of fresh air to see their humanity through it all and to be alongside a doctor who was comfortable working with that. I too began to appreciate the twenty-three get-well-soon cards on Mr. Z's wall. I congratulated Mr. X on his wife's pregnancy. I spoke about rugby, appreciated bright pyjamas and greatly gained from the entire experience.

It can be intimidating to acknowledge patients for the human beings they are – imperfect, looking forward to life, loved by someone and terrified by disease. However, our pursuit of compassion encourages us to dance with the professional and personal, a constant balancing act, allowing us to become better doctors and better people.

Cancer diagnoses are hard. Seemingly healthy individuals come to doctors to make sense of a random constellation of symptoms. You have no definitive cure to offer them, no long-term medication, no lifestyle suggestions. All you have is cancer. Empathy is needed but empathy alone may not be enough. However, cancer treatment can be even harder.

Convincing patients that medication which evidently damages their body might be the only thing that can save them, is...challenging. Again, watching seemingly healthy individuals become overtly sicker, at your hands, is emotional to say the least. Regardless, at the end of the day, with cancer diagnoses and cancer treatment, there is still a strong element of hope. These patients *can* get better. Sometimes, the evidence is strong enough to suggest that they *will* get better.

Palliative treatment is a bit different. I arrived at LOROS (The Leicestershire & Rutland Hospice) and introduced myself to the medical team that day. I went on the ward round with the senior registrar. The first patient we saw came into the hospice for palliative treatment of Acute Myeloid Leukaemia. Evidently, I expected the doctor to show compassion, concern and consideration. However, I soon realised that too would be...challenging. We walked into the room and the patient was asking to die. He looked us in the eyes, with what seemed to be the remainder of his strength, and wholeheartedly begged for death. This was confusing and unanticipated.

Compassion, from his perspective, would be acknowledging his suffering and showing him how to die. My voice, along with my legs, hands and morals, shook profoundly. The doctor, conversely, was unphased. With a level-head, he began to ask the patient about his symptoms – breathlessness, fatigue, pain, anxiety, crises of faith. He did a full palliative work-up on the patient and began to create a management plan to maximise comfort in his final stages of life.

In my awe, I visibly saw the patient regain strength, character, humour and dignity. This was unlikely compassion. Implicitly, the patient came to the doctor vulnerable and needing help. This help is best shown by ‘meeting their anxiety with calm, fear with professional interest and pain with uplifting kindness – not matching their distress with our own.’<sup>4</sup> Ironically, it seems cruel to show compassion in the final stages of life. It seems naive to believe your small actions and gestures will make any difference to someone in the midst of their suffering. Resultantly, that has the knock-on effect of making clinical encounters cold, detached and dispassionate. Here, sat in the back of a patient’s room in a hospice, I saw the courage it required to uncover compassion to someone who seems to no longer need it. It was necessary, it was gracious and it was unexpected.

In cancer and in clinical practice as a whole, compassion can be both a breath of fresh air & a slap in the face. It is the emotional pull you feel when you meet a man with severe dementia who sings every time he is scared. It is both a rude awakening and the morning sun. It is the smile on your face when you meet the cancer patient who wears a suit every time he comes for chemotherapy. It requires us to delve into our humanity, and empty out ourselves in order to establish a

connection. It requires us to feel a patient's pain as our own but still be professional, proficient and carry on.

No matter how hard we try to evade it, compassion finds us and hangs on for dear life. Like all humans, doctors have physical limits, 'neither pride nor professionalism can overcome them.'<sup>5</sup> Unlikely, unplanned and unexpected; my recollections have shown me that compassion in clinical practice reminds us of both our humanity and mortality.

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## Compassion to patients through mealtimes

by Faadumo Osman

*My name is Faadumo Osman and I am a first year medical student at the University of Leicester. When I am not immersed in the ever growing workload of medical school, I love to read, cook, go to the gym and spend time with my loved ones. I also love visiting my local coffee shops where I can relax and unwind with a good cup of coffee. Maybe one day, I'll complete my goal of visiting all the coffee shops in Leicester.*

*“Cum Scientia Caritas”* – Scientific Care with Loving Kindness.

This motto from the Royal College of General Practitioners beautifully summarises the basis and importance of compassion in healthcare. Doctors are expected to use their vast knowledge in the medical field to ensure care is provided holistically. Additionally, by forming relationships with patients, doctors can create a calm atmosphere for the patients and themselves.

There are many definitions of compassion and generally, compassion can be described as *the concern for the wellbeing of others* (Stanford Medicine).

As summarised neatly in the paper ‘Guarding against dispassion for doctors in the NHS’, compassion cannot be ‘prescribed, measured or given in a bottle’ (Das, Charlton 2018). This means compassion is not simply something that can be created on the spot. It must be learned through experience and there is no formula to it. This further illustrates that compassion forms the basis of healthcare and is embedded in healthcare. Compassion also involves forming relationships with patients and delivering

care through these relationships by being aware of the patient's needs (NHS England/Nursing Directorate 2013).

It is essential that we understand the significance of compassion and how it can affect the ability of doctors fulfilling their duty in delivering the best possible care for patients.

### My observation of compassion within healthcare

During my second year of college, I decided to volunteer as mealtime assistant/ward support at Leicester Royal infirmary to support my application as a prospective medical student. Volunteering allowed me to have a better understanding of the medical field and the importance of doctor-patient relationships.

However, as time progressed whilst volunteering, it was evident to me through my observations how incredibly vital compassion is in medicine and how it can help both patients and their healthcare providers.

Volunteering as a mealtime assistant/ward support granted me the privilege to observe the importance of compassion in healthcare. For instance, one of my roles included delivering the patients' foods on time and collecting their trays with my colleagues. Doing this under a time frame was quite difficult as patients would be restless if we were slightly late. Our collaborative effort allowed us to calm patients and help them with their needs.

### The significance of delivering food on time

Delivering food on time may seem like a miniscule thing you can do for a patient but I digress. Many of the patients I have met often had visitors during their mealtimes and this was a way for them to socialise. Something as minor as delivering food on time

can help the patient feel elated as it enables them to interact with others in addition to them escaping their usual confined environment. You see, food provides comfort for many. As a result, being compassionate even in the smallest ways can improve a patient's experience in the hospital.

For instance, in a particular bay in the ward, I noticed the patients there would eagerly wait for their meal to come. When it arrived, happiness crept up the patients' faces and I could not work out why for a long time. Slowly, as I started to focus more on these patients, I noticed that their happiness came from socialising with each other during mealtimes. For them, it was a conversation starter to talk about their meals whilst watching TV together. This allowed me to see how important something as simple as delivering food on time can affect their social time.

The notion that mealtimes can be seen as a social event is further explored in the study 'Can trained volunteers make a difference at mealtimes for older people in hospital? A qualitative study of the views and experience of nurses, patients, relatives and volunteers in the Southampton Mealtime Assistance Study'(Robison et al. 2014). According to this study, mealtime assistants can also act as a point of social interaction to patients and therefore increase the quality of care for patients(Robison et al. 2014). This further highlights the importance of mealtimes to patients, hence why food should be delivered on time.

Delivering the patient's food and collecting the trays also allowed me to witness patients being treated by their doctors. I remember being in awe over one of the doctors due to how compassionate yet professional she was. The doctor spoke so gently to her patients. She never dismissed her patients and most importantly, she listened. For instance, through communication, she had built idealistic relationships with her patients simply by tending to their

needs, utilising the concept of compassion in everything she did. Consequently, I learned that by adopting acts of compassion into my work, patients are more likely to trust me as a doctor.

Additionally, my role involved preparing beverages and snacks for the patients. Occasionally, whilst preparing the patients drinks, I would stumble upon the patients' loved ones, guiding them to the patients. By remembering what the patients would usually order or willingly making the effort to acquire something for them, I noticed patients became more relaxed and appreciative of me through these acts of compassion. It is important to note that a positive attitude shown to patients can better their mealtime experience(Hartwell, Edwards, and Symonds 2006).This further reinforced my understanding of showing compassion to patients.

### The sombrous side of mealtimes

Despite this, mealtimes were not always a joyous occasion to many and this was mainly due to them being restricted to what they could eat. Many patients could not feed themselves and some had to have pureed meals otherwise they would be unable to swallow their foods.

One particular memorable patient for me was a gentleman who was fed pureed food through a straw. This was a shocking experience to me as I was not aware of the different methods patients are fed. Losing the ability to feed themselves often led to the patients feeling as if their dignity has been taken away from them. Witnessing how the doctors treated the patients in a compassionate manner further illustrated the importance of compassion.



### Dealing with difficult patients

Throughout my experience, I dealt with patients being angry and frustrated with me when I delivered the wrong meal. I particularly remember one patient that snapped at me when I delivered his meal. He exclaimed that he did not order the meal. I apologised and spoke to the housekeeper where he went to the patient and explained that he did order the meal. The patient then began to argue and acted rashly to the housekeeper.

This was a unique experience. I was amazed by how the housekeeper handled this situation by reacting calmly and being compassionate hence settling the patient down.

The housekeeper then explained to me that sometimes, patients often act rashly as they are going through a lot. Just showing compassion can help settle the patient down.

This is further reinforced in this quote by Das and Charlton in their paper 'Guarding against dispassion for doctors in the NHS':

*'Nonetheless, regardless of how impatient, rude or demanding our patients can be, it is essential to remind ourselves that they are in a position of great stress and suffering. If they were content, then they would not behave in such a way. It is the acknowledgement of patient distress that can minimise tendencies'*

### The significance of mealtimes

The meals that patients receive are related to their treatment process, as a good balanced diet is a vital part for the recovery of patients(Hartwell, Edwards, and Symonds 2006). Unfortunately, malnutrition is prevalent in many patients, particularly, older patients whereby 39% of them are malnourished(Robison et al. 2014). Malnutrition can occur due to the hospital environment and barriers, such as the distance of the kitchen in the ward (Robison

et al. 2014). Showing compassion to patients can allow patients to overcome any barriers that may hinder their mealtime experience (Robison et al. 2014). This further illustrates the importance of compassion during mealtimes.

## Conclusion

In conclusion, being compassionate to patients can help close the gap between patients and doctors, potentially improving the environment in which patients are exposed to.

My experience enabled me to understand the significance of compassion and the power it has in the medical field. I highly encourage anyone to volunteer at your local hospital to help understand the patient perspective.

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## **Compassion to Ourselves - Where can We Start?**

by Tanvi Ambulkar

*I am Tanvi, a junior doctor from Singapore currently working in Nottingham. Having graduated from Leicester Medical School recently, I am navigating the transition from student to doctor with equal measures of excitement and nervousness. I am passionate about writing and poetry - the written word allows me to express myself freely and honestly. My other hobbies include discovering new cafes and nature photography, both of which I hope to do plenty of throughout my medical career!*

Compassion to ourselves is perhaps one of the most integral yet most inevitably condoned soft skill in everyday medical practice. The emerging popularity of practices such as mindfulness and meditation have attempted to bridge the gap between self-care and care for others. Despite this, sentiments such as guilt, frustration and even shame are often associated with having the intrepid desire to care for ourselves.

In a profession where industrious and perseverant individuals are decorated, it becomes challenging to realise the limits that we ourselves possess. In the simple act of caring for a patient, we are willing to traverse the extra mile to ensure that we deliver the best possible care. Regretfully, most healthcare professionals tend not to subject their self care to the same exacting standards. In the midst of buzzing beeps and prioritising paperwork, it becomes easy to forget to take care of ourselves. Whether this means taking a break and eating your favourite meal or comforting a colleague in distress, there are subtle ways to display compassion both to ourselves and to those around us. The fast-paced professional environment instils in each of us a sense of purpose and provides meaning to our lives.

Yet, a work-life balance is emphasised and underscored by experienced healthcare professionals because taking a break and having a moment to ourselves is just as important. When we take the time to look after ourselves, we are in fact acquiring the strength to provide better care to our patients.

Personally, as a medical student, my preferred way to unwind is to go to the gym for half an hour for a quick sprint. This is not only invigorating and energising, but it also clears my mind, takes the edge off the stresses of the day and provides me the energy to remain productive for the remainder of my day. Every individual has activities that they enjoy and it is crucial to find the time to indulge these interests.

I have always found that the joy of being in a career like medicine is multiplied when you have the opportunity to share it with others. Whether this be in the form of helping your peers, teaching your juniors or acquiring pearls of wisdom from seniors in the field, there is always more to learn and discover. And interestingly enough, this curiosity to discover stems from compassion, a burning compassion to ameliorate the lives of those unwell.

In a sense, some would argue that our desire to extend compassion to others originates from a selfish motive to make ourselves feel better. And in theory, it is indeed difficult to refute that we help others with purely selfless intentions. The other way to look at this is that when we feel better about ourselves, when we feel rejuvenated and nourished, we put ourselves in the best possible position to empathise with suffering and extend compassion to those around us.

In my personal experience, I have realised that a kind smile and a gentle demeanour work wonders with many patients. But is good bedside manner synonymous with being compassionate?

Compassion is a difficult sentiment to pin down semantically. It encompasses empathy, love for others and ourselves and a humane desire to connect with others. As medical professionals, we are constantly faced with situations that are both emotionally difficult and draining. Whilst it is important to take a step back and detach ourselves from what is happening, it is also important to consider deeply the way we respond to different situations. This form of introspection is only possible if we truly understand our own emotional machinery.

Compassion within ourselves enables us to express ourselves more honestly and makes uncomfortable emotions more bearable. Whilst our default “fight or flight” response may direct us to either avoid or confront uncomfortable situations, compassion enables us to put the situation in context – why do we feel certain feelings? Why do others feel certain feelings? The only barrier to a contextual understanding of most situations, especially in a busy workplace, is time. Healthcare professionals are constantly in a flurry of completing jobs, attending to patients, completing referrals – too busy to ask ourselves how WE are. And just maybe, if we incorporate this single moment into our day of asking ourselves how we are coping and truly check in to our feelings, we may see an improvement in our own efficiency.

I find it incredibly intriguing that despite compassion being one of the championing qualities of a doctor, and in fact one of the qualities I underscored in my personal statement whilst applying to medicine, it is so shied away from in actual practice. The most unnatural times to display compassion personally is in stressful situations – as humans, we are evolutionarily adapted to protect ourselves from adverse outcomes or events. When I have encountered such scenarios, my primary focus is the resolution of the issue at hand. As a medical student, presenting patients on ward rounds is excellent practice and a great learning opportunity.

Occasionally, I have found myself being incognizant of certain aspects of the particular patient I am presenting either because there has been an acute development or because the case itself is particularly complicated. In such a situation, it becomes difficult to imbue the situation with compassion, especially towards ourselves, as the natural response might be to feel some sense of guilt or even shame for not knowing. As these scenarios have arisen on multiple occasions, my reflections have now prompted me to consider the situation in a different light. What if I assure myself that I have done the best I could possibly have with the available resources and time? What if I practice and refine my history taking skills so I am better equipped with the most important information when it is required? Both of these realisations in some way encompass a more compassionate way of looking at a situation which can easily spiral into a self-fulfilling prophecy of being self-critical and frustrating.

When I envision my (hopefully long and fulfilling) career in medicine, I try to think of the things that will keep me grounded and happy. I find volunteering for important social causes not only a personally gratifying experience, but also something that helps me cultivate compassion. Whilst as a medical student or even a fully-fledged consultant it is perhaps impossible to have experienced the entire spectrum of diseases that can affect the human body, it is certainly possible to gain insight into the way people respond to physical afflictions.

Whilst amelioration and alleviation of all human suffering is not an attainable objective, a better understanding of human nature is possibly the most beneficial skill that a healthcare professional can possess. I have witnessed this first hand in the care of patients diagnosed with terminal illnesses. Especially in patients diagnosed with life-curtailling conditions such as cancer, there is an inordinate emphasis on 'medicalising' the patient rather than

taking the time to understand their priorities. For instance, some patients are less worried about the prognosis about the condition but are more concerned about the impact such a grave diagnosis will have on their families.

This is precisely where compassion becomes a focused practice – rather than having a broad brushstroke approach for every individual and situation you meet, it is essential to have a more nuanced understanding of both patients and the complex situations which are often so prevalent in medicine. I find that the best way for me to do this is to talk with my family members and loved ones about the way they would like to be treated and the standard of care they expect. And surprisingly enough, most of my conversations reveal that individuals want to be treated on a human level with empathy and understanding.

Another active approach to developing compassion within ourselves (if this is a skill we perceive not to already possess) is to objectively analyse the way we treat others. This becomes even more important in situations where environmental factors such as fatigue, lack of nutrition and long shifts inevitably influence the way we behave<sup>1</sup>. Whilst it is an unreasonable expectation to be consistently happy, a baseline level of almost professional compassion is not only required but expected. The individuals we encounter on a typical work shift, whether it is our colleagues, senior consultants, patients or family members, are generally oblivious to our own mental mind storms.

Rarely, individuals will notice that you are tired after a long shift or upset because a disgruntled patient shouted at you. However, being impolite or impassionate will be noticed and has the potential to have a lasting impression on patients. So how do we

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<sup>1</sup>Go-gale-com.ezproxy3.lib.le.ac.uk. (2020). *Shibboleth Authentication Request*. [online] Available at: <https://go-gale-com.ezproxy3.lib.le.ac.uk/ps/i.do?id=GALE%7CA392096859&v=2.1&u=leicester&it=r&p=EAIM&sw=w> [Accessed 29 Jan. 2020].

manage this almost unfair dichotomy? With three simple steps:

(1) *Manage your expectations*: Medicine is understandably, a tough career which routinely deals with human lives, suffering and a plethora of emotions. Whilst we could be used to receiving praise for doing well in exams from school, expecting gratitude constantly is likely to be more painful than productive. Remind yourself that you are constantly doing the best you can and persevere.

(2) *Diversify and explore life*: Having interests outside of medicine such as a sport or other social activities can help high-achieving individuals feel like they have a purpose. This becomes especially important on days when you aren't feeling so great about work or you have had an unavoidable conflict. Having an activity that you love and enjoy doing takes your mind off the stress of work and can actually boost your own productivity and energy levels.

(3) *Treat others as you would want to be treated*: This point does not guarantee the reciprocal return of good behaviour, but it is a stable way to maintain consistency in your interactions with other individuals. Even on days that we are extremely tired, we rarely shout or get angry with ourselves. Instead, we choose to treat ourselves to a warm cappuccino, peruse a new book or simply opt for a good night's sleep. So why should our approach with others be any less kind?

Compassion fatigue is a phenomenon used to describe the lack of ability to demonstrate compassion both with ourselves and others due to personal or environmental factors. Displaying compassion consistently is challenging especially with the workload we are often faced with and the interprofessional conflicts that can invariably arise by virtue of differing opinion. Despite these



barriers, we can find ways to be compassionate through constant reflection and introspection of our attitudes.

*Do you find yourself becoming increasingly irritable? Do you find yourself constantly fatigued and unable to empathize with what anyone else is going through?* If you find yourself answering in the affirmative to either of these questions, emotional exhaustion might be one of the main issues at hand.

Emotional exhaustion is a product of devoting too much time to everything and everyone around us at the expense of ourselves. A consequence of this is being unable to exercise compassion and patience in our interactions with others. Combatting emotional exhaustion is a simple three-step process:

(1) *Recognize it.* Acknowledge that you are emotionally exhausted and may need reprieve from your daily tasks.

(2) *Allow yourself to have a break.* A break is not necessarily limited to idle lazing – it can include a spectrum of activities from watercolor painting to learning a new skill (e.g. experimenting with Asian recipes).

(3) *Devise an action plan to preclude emotional exhaustion in the future.* Make a note of the warning signs (e.g. deteriorating motivation, poor time-management, increased anxiety and irritability) and think about devoting some time to yourself when you recognize these signs within yourself.

With my observations of those around me, I have noticed that the most compassionate of my colleagues take the best care of themselves. This can include simple things like eating meals on time, balancing hobbies with work, and saying no to things that can potentially deprive them of their valuable personal fuel which

they need for the other important activities they partake in. In simple terms, compassionate individuals can often achieve a work-life balance. Whilst the work medical professionals do is important and life-saving, there needs to be an element of detachment.

For instance, taking to heart criticism about your work and subsequently letting it define you is detrimental to your well-being. Being compassionate ironically involves taking a step back sometimes and being unapologetic about taking care of yourself for a change. Nurturing yourself allows you to approach work with a fresh perspective. Self-care provides the emotional nutrition you require to withstand the various difficult and sometimes intensely emotional experiences that all healthcare professionals experience throughout their career.

Studies have repeatedly shown that compassion is one of the most powerful predictors of success in medicine when combined with academic knowledge and practical application. In order to allow ourselves to bloom into the clinicians we aspire to be, compassion, especially to ourselves can help us derive fulfillment from the meaningful work we do.

This job satisfaction has so many positive benefits in the form of reducing burnout, increased productivity and efficiency, and greater patient satisfaction.

In times where everything has become so competitive and fast-paced, let's take the time to breathe. Let's take the time to enjoy the very moments we have worked so hard for. Let's take solace in the fact that the singular way to be a good clinician is to be compassionate to ourselves first because that is the only way we are able to extend this kindness towards our patients.

## **Make Room for EQ (Emotional Intelligence)**

by Parisah Hussain

*Parisah, pronounced as Pareesa, is a Persian name which means fairy. I am a 23-year-old massive foodie who was born and raised in Enfield, North London. I am normally described as a bubbly medical student, who enjoys playing golf in her free time, who will never say no to an outing, and also aspires to become a managing GP partner of a practice. Also, I have completed an intercalated BSc in Management from Imperial College London and currently in my penultimate year of medicine at Leicester Medical School.*

### **My Role in Medicine**

I have been studying medicine for over four years; the first clinical year included clinical placements which explored specialities such as orthopaedics, surgery, general practice, psychiatry and general medicine. I am currently in my second clinical year which includes obstetrics and gynaecology, paediatrics, oncology and palliative care, neurology and special senses and integrated care placements.

Throughout my degree, I have realised that a doctor's role is not only about diagnosing and prescribing medication; it is a complex, ever-changing career which involves providing trust, safety and taking prompt actions when a patient's well-being is compromised.

Although the medical management of the conditions that I have seen is crucial, the psychological and social elements are equally as important to consider for every patient, some of which may be very complicated and difficult to discuss and resolve. Therefore, I

believe that emotional intelligence and not just compassion alone is needed, more than ever in 21<sup>st</sup> Century healthcare.

### Emotional Intelligence

As described by Daniel Goleman, emotional intelligence, which is commonly abbreviated as EQ (emotional quotient so it can be compared to an individual's IQ), consists of four domains:

- self-awareness
- self-regulation
- social awareness
- relationship management

These can be categorised into personal and social components (Goleman, 1995).

With regards to *personal component*, the individual themselves need to be aware of their own emotions and to be able to regulate their behaviour upon how they feel.

The *social component* entails the individual to be aware of other people's emotions and behaviours in the room, thus being able to maintain strong relationships with them overtime.

How do I define emotional intelligence? For me, emotional intelligence is having the ability to be aware of one's own emotions, other people's emotions around you and therefore controlling your behaviour and the way you interact with other people. I believe that self-awareness is the most important domain. If an individual does not have self-awareness, then they cannot practice their development of the other three domains of emotional intelligence.

Moreover, this concept consists of twelve competencies, including empathy, which are needed for effective leadership (Goleman, 2019). They can be categorised according to the four domains:

- self-awareness  
emotional self-awareness
- self-regulation  
emotional self-control  
adaptability  
positive outlook  
achievement orientation
- social awareness  
empathy  
organisational awareness
- relationship management  
influence  
conflict management  
inspirational leadership  
coach and mentor  
teamwork

### Emotional Intelligence in Healthcare

Emotional intelligence is a critical concept, which is commonly discussed in the business and financial industries. However, within the healthcare industry, especially the NHS, it is commonly overlooked. Healthcare professionals are simply unaware of the concept, do not fully understand the meaning of it, or confuse the definition with empathy or reflection. I personally have not heard anyone mention it whilst I have been on placement. Even when I ask simple question, “Have you heard of emotional intelligence?”, “Have you attended emotional intelligence

workshops?” The majority of healthcare professionals, especially doctors, have not heard of it before.

Based on my time on clinical placements, I strongly believe that emotional intelligence should not be seen as a soft skill when developing tomorrow’s doctors. Soft skills are actually much harder to master compared to hard skills. The term soft skills should even be re-branded into hard skills.

### Being Emotionally Intelligent towards Patients

As a future doctor, there will be times when I have to be prepared and demonstrate emotional intelligence when breaking bad news unexpectedly to a patient. For example, I attended the Rapid Access Lung (RAL) clinic with a consultant respiratory physician and specialist respiratory nurse at Glenfield Hospital. We spoke to an elderly woman with a WHO Performance Score of 3 who recently had an MRI scan of her heart; it revealed a suspicious mass in her lung. After having an x-ray and CT scan of her chest, she was informed that she has right lung cancer which has metastasised to her left lung. Her staging score was T4, N2, M1.

At this point, I was expecting the consultant to discuss having chemotherapy and surgery, however he informed the patient and the nurse, with high levels of emotional intelligence, that he is unfortunately unable to offer any form of treatment to the patient because the malignancy has metastasised, she has other co-morbidities such as right heart failure with systolic dysfunction and starting chemotherapy will actually reduce her quality of life.

I felt upset after the consultation because the patient felt like her whole life was turned upside down as soon as she realised there was no definitive treatment for her condition. During medical school, I have been taught to use the SPIKES model (Setting, Perception, Invitation, Knowledge, Empathy, Summary/Strategy)

(MDU, 2019) as an effective framework when breaking bad news, as this is an aspect of healthcare that many professionals fear. However, I believe that the concept of emotional intelligence should be linked with the SPIKES model in the curriculum in order to understand the bigger picture, as many medical students just use the model as a guideline to pass exams.

On the other hand, being too emotionally intelligent has its own problems as well. I personally struggle breaking bad news as I tend to let my own emotions get in the way, especially during that consultation. Consequently, I need to learn to be more resilient and find a balance between being compassionate but emotionally detached.

Despite the situation, it was also great to see that the consultant demonstrated high levels of emotional intelligence towards his colleague as well his patient. There have been a few events where I still see doctors who treat their patients very well. However, they show very poor and little emotional intelligence towards their colleagues on the wards and in theatre. For instance, I attended an antenatal clinic with a consultant obstetrician and a healthcare assistant at Queen's Hospital. Throughout the clinic, I noticed that the consultant was consistently treating the healthcare assistant badly; he was always talking over her; he looked down at her and became argumentative whenever she made a mistake filling in the forms when she was trying her best to understand what he wanted her to write. There was no amicable relationship. We should not forget that it is vitally important to treat our colleagues well in order to achieve high quality care for the patient.

I have always been reminded that it is vital for doctors to have empathy in 21<sup>st</sup> Century healthcare. Empathy is a key non-clinical skill to develop and improve in my career. During medical school,

we are taught to be empathetic, especially during communication skill simulations. However, what I have noticed is that whilst being on clinical placements, medical students are sympathetic but not empathetic towards patients. It is a word which is commonly overlooked, and society assumes that all healthcare professionals are naturally emotionally intelligent towards their patients and colleagues.

For me, it is quite common to mix up both skills and assume you are portraying one but actually showing the other. How could I possibly understand what someone is going through? How can I put myself into their shoes? In the future, I will avoid saying “I understand” or “I know what you mean” when communicating to patients.

### My Perception as a Future Doctor

Overall, my clinical attachments during medical school made me realise that being a doctor is not actually about saving lives, everyone is born, and everyone dies. This is the sad reality. No one can live forever.

Yes, we are perceived to be the most trustworthy members of society, however doctors are not superheroes. Medicine is actually about improving the quality of life for individuals and ensuring that they live their last moments of life in comfort.

Additionally, to ensure that the next generation of NHS doctors are compassionate, they need to practice their emotional intelligence on a daily basis. More importantly, in order to develop more emotionally intelligent doctors in the future, the barriers and facilitators to developing emotional intelligence in 21<sup>st</sup> Century healthcare must be identified. We all need to make room to develop our own level of emotional intelligence.



This has changed my mindset and the way I will practice emotional intelligence whilst working as a medical doctor after graduating from Leicester Medical School. I should no longer see myself as a hero saving the day. I will embrace all of the challenges this exciting career will offer me.

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## **Being There**

by Matthew Baer

*Matthew Baer is a fourth-year medical student at Creighton University School of Medicine Phoenix Regional Campus. These past few months, he's been applying to family-medicine residency programs and interviewing around the country. In his free time, he enjoys hiking in the mountains near Phoenix, training for the next marathon or rock climbing at the local gym. "Going to medical school has made me more aware of the need to slow down and process my experiences. I started journaling during my first year of medical school, then, in my third year, began to focus on the things (power dynamics, death and dying, burnout) I saw during clinical rotations. This piece began as one of those journal entries."*

Question: What is the most read book in a psychiatric ward?

Answer: Based on my observations, it's the Christian Bible. During my psychiatry rotation in the third year of medical school, I saw so many patients researching, reading and preaching the word of God. Clearly, in those pages they found something they needed: vengeance against those who'd wronged them, a secret prophecy, confirmation of their sanity. Or maybe they saw the central message: "You're loved. We (God, humans, nature, whatever) care for you and will take care of you. We understand you."

Seeing these patients cling to the Bible felt moving and deeply sad--painful, really. A younger, more innocent me might have seen some grace and faith. But, honestly, all I saw was emptiness--in the sense that patients in deep despair, who've

been told, "Your mind is broken," "Your body is broken" or "You're going to die soon," lack something in their lives: real human connection.

My third-year rotations have taught me that interacting day after day with people in pain does one of three things to you. The first two are (1) burn you out and (2) shut you down. I believe that these things unfold slowly; we don't see them until it's too late. That's why our teachers and mentors have blasted "balance" and "mindfulness" into us. They know. They're warning us about a coming storm.

I have suffered from this storm's effects over the last year. I have felt myself detaching and growing numb to my patients. I think of the pregnant heroin addict who was vomiting on my arm and wouldn't sit still for a CT scan. Really, all I wanted was for her to shut up and stop jerking us around; I found myself ignoring her complaints of being too nauseated to lie flat. Feeling angry, I retreated when maybe I should have tried to comfort her instead.

I have also started to retreat into myself. I've thrown more and more energy into cheap thrills that get me out of my head for a minute. The more time I spend watching patients in pain, the more I need to numb myself by binge-watching Netflix or mindlessly surfing the Web.

On the other hand, I've also found the third option: I can be uplifted. Making that happen takes a lot of work, but at the same time, it offers something spiritual.

Recently, on a slow day, I talked about this with a surgeon.

"Based on my personal experience, I'd never recommend medicine to anyone," he said. "I'm tired and lonely at the end of

the day. I'm single, and I don't have enough free time to meet anyone outside of work. My health is suffering, and I feel like a pawn being moved around by hospital administration."

"So what keeps you coming back to work every day?" I asked.

He thought for a moment. "There's something about helping people in need--not just helping them to get rich, or selling them something, but really helping them--that makes it all worth it."

His words affirmed my growing sense that, in order to have a fulfilling life in medicine, you not only need to create balance and wellness for yourself; you also need to embrace connections with people during your work day.

Last week, I had a chance to test this hypothesis.

In the ICU, I helped care for a lady named Rita who'd had a very complex surgery, with multiple complications. A few days after the surgery, she was improving, but was still on a breathing tube. She was so swollen, she looked like an inflated water balloon, her skin so fragile that I was afraid the pressure from my stethoscope would rip it. During rounds, I noticed her watching, in what seemed like mute terror, as nurses and residents swarmed around her, checking the ventilator settings, recording the IV drips and taking blood.

One morning, after Rita's physical exam was done, I sat with her and allowed myself to feel her pain. Without thinking, I reached out and held her swollen hand.

She tried to mouth words around the breathing tube, but I couldn't make them out. Gripping my hand tighter, she silently began to cry. I tried to look calm, peaceful and loving, but I know that some

part of my face reflected the horror I felt--not the horror of holding her hand, but of really entering into her experience. It was a living nightmare: unable to talk, trapped in a broken and swelling body, barraged by beeping machines and daily needles and, worst of all, deprived of nearly all human contact.

That night I walked home in a trance, feeling strangely energized and expansive. On my evening run, as I felt my feet pounding the pavement, I also heard the steady beep and whir of Rita's monitors.

As unpleasant as it was to view the world through Rita's eyes, I also found something about the experience empowering--and so, I believe, did she. Every morning, I would bounce awake to go check on her and provide my brief daily hand-holding. She would visibly brighten when I came in. While tracking her fluid intake and output like a hawk and ensuring that her wound was healing, I also monitored her well-being and titrated my dose of connectedness accordingly.

Two days after we removed the breathing tube, when Rita could finally talk again, she looked at me and hoarsely murmured, "Thank you."

Her eyes shone with a peace and joy that is hard to describe. It made me feel like crying, dancing and laughing, all at the same time; I felt a deep sense of connection. It was like gazing into the eyes of God.

Since then, I've tried to keep moments like these at the forefront of my mind. Doing so has taught me a few things.

I've learned that I'm human. Really, painfully human. I'm afraid of the things most people are afraid of: pain, suffering, loneliness

and loss. I've learned that if I'm exposed to those things without taking time to reflect on them, I will burn out and shut down. But I have also learned ways to ease their toll on me.

I am working at building up a supportive network of family and friends by sharing my feelings and experiences with the people closest to me. I'm looking for opportunities to use my knowledge and compassion to give relief and respite to suffering patients. And, most importantly, as I did with Rita, I've started entering into their experiences in order to connect with them more fully.

I am really glad that so many patients find comfort in the Bible. But I hope that some will also take comfort in my presence and in my willingness to be there with them when life is hard.

As I'm starting to realize, our connection to each other just might be the greatest gift medicine has to offer--to me, and to all of us.

## Reference

From:

*Pulse — Voices From the Heart of Medicine,*

Website: <https://www.pulsevoices.org/> (which publishes personal accounts of illness and healing.)

Link - <https://www.pulsevoices.org/index.php/pulse-stories/2152-being-there> (13th of December 2019)

Thank you to Pulse Voices & Matthew Baer for permission to publish this

## **An Ounce of Empathy**

**(My grandfather died of covid-19. More empathy from everyone may have prevented such deaths in this pandemic)**

by William Liakos

*William Liakos is a third-year medical student at Donald and Barbara Zucker School of Medicine at Hofstra/Northwell in Hempstead, New York.*

I am a medical student in my third year of studies. For medical students, this is the point at which, after two years of book learning, we rotate through hospital clerkships that give us our first experience of delivering hands-on care to inpatients.

Earlier in the year (it feels like many lifetimes ago), I read that covid-19 was “just the flu.” We heard from scientific sources and popular media that other maladies were much worse, and that it would be a mistake to overreact to this one. Like many people, I accepted these assurances without too much concern. It all seemed a bit remote to me — the way I imagine issues like food stamps may seem to a politician who has never needed them.

But now all of that has changed for me.

It’s not just that my hospital clerkships have been changed into online electives. I wish it were only that.

On April 3, my grandfather died of covid-19.

He was the last of my grandparents still living, and we were close. His name was John Diaz. Growing up, I called him “Mydada,” and over the past few years, “JD.”

He was 82 and eccentric. A native New Yorker and an engineer by trade, he lived in Philadelphia and achieved success in his field, but his heart was in the arts — theater, literature, visual arts, ballet and music. His favorite, I think, was theater; in his spare time, he acted in community theater productions, and his obituary in the Philadelphia Inquirer paid tribute to his “resonating stage voice and . . . dashing physical presence.” But literature and reading were a close second.

I think of how, immediately upon seeing me, he’d always hand me a new book to read, good-naturedly saying, “Here’s your assignment,” so that we could discuss it later over the phone. Sometimes the book was a classic read like “Brave New World,” but more often it was a secondhand edition of an out-of-print book on byzantine languages, or an autobiography written by the obscure dictator of a small island nation. He loved learning, continuing to take college classes well into his later years, and I think this was his way of trying to pass it along.

I knew that my grandfather’s chronic obstructive pulmonary disease would put him at high risk of complications or death if he were to catch the virus, but I still couldn’t imagine that he might actually be affected. It was truly too scary to think about.

As a medical student, I’ve absorbed many lessons in empathy. Still, it took this deep personal loss to fully bring home to me the pandemic’s effects. Now I understand much more clearly what I saw months ago in the videos from China, which showed doctors dying of the virus and lockdowns choking off normal life. Now I also can feel, in a visceral way, the pain, fear and grief that the people in those videos must have felt.



I know that countless others now share this massively heightened sense of urgency about the coronavirus. But I keep wondering what factors blunted our awareness at first. I've concluded that a major deficiency in our country's early response was a lack of empathy.

It seems to me, looking at the big picture, that the defining response in the United States was an inability to put ourselves in the shoes of someone else who lived across the globe. What if we'd imagined ourselves living the plight of Chinese residents trapped in Wuhan during the first stages of the pandemic, or of the Italian doctors forced to triage ventilators and deny them to people over a certain age? Might a deeper sense of empathy and urgency actually have led us to put together a response that was more pragmatic, and more effective?

If we had recognized the events in other countries, felt their pain and heeded their warnings, and then responded proactively with testing and other preparations, as did South Korea and Singapore, I believe that we could have achieved immensely better results than what we're now seeing, with our hospitals and clinicians overwhelmed, and countless people who like me are grieving for lost loved ones.

Amid this crisis, I believe that we as a nation need to choose between two conflicting impulses: to turn inward and blame "outsiders" for our current troubles; or to come together as a member of the global community and to reach out and embrace the experiences of other people in other nations, through empathy and compassion.

For me, the choice seems clear. I keep coming back to Benjamin Franklin's maxim "An ounce of prevention is worth a pound of cure." I believe that an ounce of empathy could have been — and

in many states in the country might still be — our best method of prevention.

I can't help thinking that, if we had exercised that kind of empathy and had prepared better for the pandemic, I might still have my grandfather with me today.

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From:

*Pulse — Voices From the Heart of Medicine,*

Website which publishes personal accounts of illness and healing.

Link - <https://pulsevoices.org/index.php/stories/an-ounce-of-empathy>

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*This article originally appeared on (22<sup>nd</sup> April 2020). Also the Washington Post 2<sup>nd</sup> May 2020.*

## Compassion

by Rev'd Susan Restall

*Susan qualified as a Therapeutic Dietitian in 1968, serving in several Hospital across the country, including Great Ormond Street. She then studied for the Anglican Ministry, becoming one of the first Women Priests in the Church of England in 1994. After working for a time in the Parish Ministry, she returned to the NHS to serve as a Chaplain. She is now retired, but still enjoys an active ministry helping needful parishes*

All patients in hospital, even if they are there for a fairly minor procedure feel disturbed because they are vulnerable and outside of their comfort zone. The sounds, smells and routines of hospital life are comfortably familiar to those of us who work there, but it is a different matter for any one the wrong side of the sheets, even hospital employees.

Privacy and control over their lives and bodies has mostly gone and they become part of a system, and a system about which they may have limited knowledge. I used to wonder why patients so frequently talked about the food, and came to the conclusion that for some, it was one of the few things they actually understood.

What we all want in those circumstances is to be treated like a fellow human being who has dignity and worth. We want kindness and empathy in our weakness, our vulnerability and fear. In other words, we want compassion. What we do not want is to become, just another case, another number.

As a Hospital Chaplain, it could be said that compassion was my primary role. In a busy clinical situation, few people have time to sit and talk, but that was my primary function. I spent a lot of time just sitting listening to people's concerns about what was happening to them, and also, what was happening to those around them. I was frequently the butt of jokes from staff about Chaplains needing to get up out of their comfy seat and do a hard day's work, but actually listening to patient's fears and worries all day was quite hard work.

Apart from the worry a patient may have about their own personal situation, there are often what one might call spiritual worries. For some, it may be the first time that they have seriously considered their mortality. This may be amplified or even precipitated by being put in a bed close to someone who is actually dying or has a cardiac arrest; for someone previously unexposed to 'end of life issues', this can be a shocking experience.

Dealing with these fears are 'bread and butter' to the Chaplain but busy Health Professionals rarely have time to delve into such issues. It is good however, to consider that such matters may be going on in a patient's mind, even though they are not talking about it. Simple kindness and empathy may ease more than the more obvious of a patient's fears, and may do far more good than one ever knows.

Of course showing compassion does not mean getting over emotional about other people's distress. There does have to be some detachment, some cut off point, and that is a skill one has to learn or else, burn out, but that should never be used as an excuse not to display simple kindness. A little kindness or empathy, especially when a patient is undergoing an unpleasant procedure is of such great help to them, and after all, that is what we would want for ourselves or our loved ones.

Medicine is a fascinating profession inasmuch as it is science based, but to be truly effective, it must deal with the mystery of the human psyche, and that requires empathy and understanding.

As a Chaplain, patients would sometimes speak to me about the treatment they received from other Health Care Professionals. Often they would tell me how much better they felt when a particular clinician had visited them, even without them having administered any treatment. One knew then that simply by using compassion, the professional was likely to be, not just a Doctor, but also a Healer, and the patient had received 'good medicine'. All it took was a little compassion.

On the other hand, rarely, but distressingly, I have had patients say that a particular clinician treated them like 'a lump of meat'! Sometimes this is just the patient being a bit melodramatic, but sometimes, regrettably, the frequency with which it was said about an individual, might have pointed to the truth. Patients are not fools. They know when they are being treated as just another case, or indeed, as an interesting case, rather than an individual who is due respect and warmth as a fellow human being.

Can compassion be taught?

Perhaps, if not taught, it needs to be discussed, because, through no fault of their own, young professionals may have little personal experience of the fear engendered through the frailty and disabilities of vulnerable people, or indeed, the problems of those in situations of poverty or from a different social class than themselves. But really, it is quite simple. All we need to do is treat other people as we would like to be treated. Then, perhaps when our vulnerable time comes, as it surely will, we, too might experience the same compassion and thereby find comfort.

## **Role-Models or otherwise in Compassion**

by Anthony Joseph

*Born in Birmingham 1937, the son of an Actuary. He studied medicine at Cambridge and the St. Bartholomew's Hospital and gained his MRCP in 1966. He worked briefly in Sydney, Australia and became a GP Partner in Smethwick, West Midlands fro 1964-99 and then a locum after that. He was a Lecturer in General Practice Paediatrics at Birmingham Children's Hospital. In addition to his family, his principal recreation is genealogy and the Emeritus President of the Jewish Genealogical Society of Great Britain. He continues to live in Smethwick where he worked.*

Moving on to the bereavement care management: my first experience that shaped my attitude to a doctor's role in this condition occurred when I was a first year Medical Student at Cambridge. There was not enough room in College for all of the undergraduates and I was billeted in lodgings in the town for my first year. My landlord and landlady were elderly, in their seventies, and had not really intended to continue accepting students but had been persuaded to "just once more" and I was their incumbent. The landlord had been gassed in World War 1 and had had chronic lung trouble ever since: he was easily dyspnoeic and subject to recurrent LRTI. One day in March 1956 he experienced sudden severe chest pain and his wife had to go to the Surgery to summon their GP who arrived quite promptly, diagnosed a serious myocardial infarction, administered intramuscular morphine and left. He alleged that he had warned us that the landlord was likely to die quite soon but I do not remember him saying that.

The pain did ease and he became more comfortable but his colour was ominous, the breathing not good and it did seem that he was a dying man. At about 2.00am the next morning, and we had sat with him all the time, he stopped breathing and became more blue. I had never seen a death before so I was uncertain as to what to do. I was also not quite sure if he had actually died as our pre-clinical course had not got that far in teaching. I thought the GP had to be informed and since the landlady had no landline and mobile 'phones had not been invented at that point I sallied forth into the town to find a coin box telephone.

When located I rang the Surgery number and a very sleepy voice answered so I explained my reason for ringing. The "sleepy" voice instantly became intensely angry and hurled invective at me for disturbing him when I had been told that the man would die and he (the GP) did not need to know about it in the middle of the night. Of course in my inexperience I had not understood that. I did not report back to the grieving widow my treatment at the hands of the GP but merely said he had thanked me and he would call in the morning to issue appropriate certification! However I was appalled that that GP could have been so insensitive to a callow youth and I resolved that if I ever had to involve myself I would NEVER speak so unkindly to an upset bearer of death tidings.

In due course, now in General Practice, of course I had much involvement as we do with terminal care. Many, many times when I suspected an imminent demise I would tell the family that if it happened in an Out-of-Hours time they were welcome to telephone me (and I gave them my home number: it was never abused). I did not promise that I would always attend immediately but I said always that if they felt the need to communicate what had happened I would listen to them and try and soothe their distress. I have NEVER regretted making myself available in such

circumstances, whether officially on or off duty! Usually all that was necessary was to listen sympathetically for a few minutes and then attend the next morning for doing the paperwork etc.

I am not sure if hospital admission would have been in the landlord's best interests; he had so much lung disease that any invasive procedures might have simply added more distress before the inevitable. In retrospect I think the clinical decision to administer analgesia/psycho-calming was reasonable.

The story was published in the British Medical Journal (BMJ\*) under my name some years ago now in that publication's "Christmas edition" which is more anecdotal and sometimes about "zany" experiences rather than too clinical or scientific. I cannot remember precisely when but perhaps some fifteen years ago or more.

For me, at the time, the visiting GP who gave the landlord his injection seemed competent and professional. I do not recall him acting abruptly or speaking unkindly to us and it was only my encounter with him per telephone twelve hours later that upset me. With the benefit of hindsight and after learning some medicine, I think his clinical judgement was reasonable. It could be argued that a more "high-tech" approach should have been offered to the patient but I think (again using the "retrospectoscope") his prognosis was very poor and keeping him comfortable until his natural demise was as good an outcome as possible.

Incidentally the event "bonded" me for a long time with his widow (they had no children or siblings). She entered a Retirement Home (sheltered accommodation) in a village and I visited her regularly for about fifteen years till she died in her late nineties. By



this time I had qualified, married and we had three children. They all came with me over time when we went on holiday near the village and nicknamed her “Granny”!

The episode took place in the 1950s, and although it has influenced me profoundly ever since when I have had to handle akin situations in my practice, is it a modern enough event to include in this book.

(\*We have been unable to trace its publication in the BMJ)

The message in this story is compassion towards colleagues which is as important for good practice as showing proper compassion to patients. However it could be argued that my unfortunate experience at being the recipient of anything but compassion created a really positive way for future practicing compassion. Perhaps not the nicest learning curve but effective!

I am not a religious Jew (although I am always surprised when I consider just how many such people have trusted me to look after them) but I am comfortable in my ethnic identity. The Hebrew term for compassion (or perhaps mercy) is “Rachmonas” and the liturgy is spattered with references to the “all-merciful”. The derivation of this concept but it is epitomised by the works of the mediaeval Jewish Physician, Maimonides, who was way ahead of his time in understanding the human predicament. It has also been summarised by the Jewish sage Hillel who, when asked to summarise the essence of Judaism, replied “Do unto others ..... the rest is commentary”.

## **Kindness towards strangers: a frontline GP's personal perspective on compassion**

by Steven Levene

*Steve Levene was a GP partner in a busy Leicester inner city practice for 28 years; during this time, he was a GP trainer and an undergraduate tutor. Since his retirement from clinical practice he has continued to participate in both undergraduate and postgraduate medical education and to refine a clinical consultation model, an earlier version of which has been published.*

Comforting others with sympathetic gestures or words generally requires less effort than demonstrating genuine empathy or compassion, which convey something more substantial. During my time as a general practitioner, compassion was rarely discussed in training sessions, governance meetings or the surgery. Was this because compassion is an elusive concept to understand or did other things crowd it out? I believe that tapping into what compassion we still possess is important and possible in these challenging times.

### **Can compassion be defined?**

Definitions of compassion can differ. In the Oxford English Dictionary compassion is “the feeling or emotion, when a person is moved by the suffering or distress of another, and by the desire to relieve it; pity that inclines one to spare or to succour”<sup>1</sup>; sometimes summarised as “suffering together.” For busy health care professionals seeing a succession of patients with sometimes complex and often insoluble problems or working with challenging colleagues, repeated suffering would be unsustainable and cause early burnout. The Department of Health

document, *Compassion in Practice*<sup>2</sup>, defines compassion as, “... how care is given through relationships based on empathy, respect and dignity - it can also be described as intelligent kindness...” I prefer this definition.

Sir William Osler described two essential qualities that all physicians should cultivate, imperturbability (complete calm when under extreme pressure) and equanimity. He advised that physicians should display a “judicious measure of obtuseness”, but without hardness<sup>3</sup>. Osler’s essential qualities do not preclude compassion, but now seem incomplete and reflect a more hierarchical doctor-patient relationship.

Compassion is an abstract noun, which describes a quality or distinctive attribute possessed by someone and which is difficult to measure objectively. In contrast, a concrete noun can be physically perceived by at least one of our five senses. Sometimes we find it is easier to recognise something than to describe it. Context provides a useful framework for thinking about comprehension:

- Compassion arises from empathy, i.e. a genuine understanding of the other person’s perspective. However, is empathy alone sufficient for compassion? Consider how we respond to news coverage of faraway natural disasters. Disaster appeals compel us to imagine the victims’ suffering, and hopefully result in donations. Are such transactions empathy or compassion? I would argue that the intended recipient should be able to perceive compassion in the person possessing it, i.e. there needs to a more direct connection.
- Compassion is a means to an end, not an aim.
- Compassionate behaviour is generally enmeshed with other qualities, thinking and behaviours; levels of compassion are not necessarily directly proportionate to the success of outcomes.

- Levels of compassion vary, either within or between individuals- sometimes within a very short time frame.

Looking after ourselves, especially physically, is essential if we are to help others. The famous Latin aphorism “mens sana in corpore sano (a healthy mind in a healthy body)” neatly encapsulates this.

### **How might compassion be demonstrated?**

Most of us have the potential to be compassionate, but this is worthwhile only if it influences our behaviour. Underpinning compassion is an empathetic mind-set, in which at least three things are of central importance to the health care professional and evident to others:

1. Respecting the patient’s autonomy
2. Understanding the impact of the illness on the patient,
3. Achieving the best possible outcome from the patient’s perspective

Particular thought patterns and behaviours align well with an empathetic mindset. We are more likely to act compassionately if we adopt more tolerant attitudes, become more reflective and improve listening skills. Training and experience can encourage specific actions, such as:

- Focussing on the present and the other person(s), rather than on the past, future or elsewhere in the room, e.g. the computer screen.
- Listening carefully and being genuinely curious about the problem and its impact on others.
- Being non-judgemental by challenging possibly flawed assumptions about others and their problems.

- Remembering to moderate the tone and speed of speech, especially when others forget to.
- Being openly willing to “go the extra mile” to achieve the best possible outcome.
- Being truthful allied with tact and kindness.
- Mentally stepping back and regularly asking, “is this how I would wish to be treated?”

Perfection is elusive, but we should aim to do the above more regularly and proficiently. As with physical fitness, regular and moderately intensive exercise of compassionate thinking and behaviour will help their development and maintenance. Patient feedback, good or not so good, provides valuable perspectives on professional compassion, as well as helping self-reflection. Comments such “the doctor really listened to me” or “the doctor treated me with respect and was kind” suggest that the patient perceives that he or she genuinely “matters” to the doctor.

It is tough to be compassionate during a stressful working day, especially when dealing with a “heart sink” patient or a “challenging” colleague. We should not ignore self-preservation. Joanna Cannon has written that “compassion is something to be desired and applauded but will eat away at your sanity”<sup>4</sup>. “Stuff happens”, none of us are perfect: compassion sometimes needs to be directed internally.

### **Can compassion still thrive?**

Can compassion persist away from the learning environment and is it possible to prevent “compassion fatigue”? Compassion is more likely to remain under wraps if not valued. Sadly, the climate in the National Health Service (NHS) is becoming progressively less hospitable for compassion towards both patients and colleagues. Some whistle-blowers’ experiences suggest that compassion is not universal within NHS management.

An often-repeated mantra is that we should aspire to deliver patient-centred care. Improving the quality of patient care relies upon an increasing volume of guidance and protocols, but these may give rise to relatively inflexible care pathways and may prioritise measurable things (that can neatly populate tables or graphs in reports) over less tangible, but equally important, things. If the health care system evaluates and remunerates providers' performances mainly on the basis on readily measurable indicators and targets, then where do more abstract things of importance, such as compassion, fit in? Another possible downside is restrictions on appropriate (and sometimes compassionate) clinical discretion, particularly when deviating from official guidelines or protocols, such as by supporting patients who decline or prefer alternatives to "best practice".

The progressively increasing demands of an ageing population with more complex problems and the greater availability of better treatments (with cost implications) exert huge pressures on our financially restricted health care systems. Tough and often rushed choices have to be made. Prioritising intangible things in a mainly target-driven system is difficult when ministers and managers are seeking quick fixes for multiple sometimes conflicting priorities. Finding room for compassion in such an environment is not always easy or straightforward.

### **Final thoughts**

Being compassionate, however defined, is often challenging and may even require bravery, especially when under pressure. We should aspire to it, but also acknowledge that we cannot always achieve it.

Have I been a compassionate doctor? Over time, I believe that I became a more engaged listener, less judgemental in my thinking

and more tactful in my behaviour; maybe this is progress. If so, then I should be grateful primarily to my patients, who have been my best teachers.

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<sup>3</sup>Osler W. Aequanimitas. Online: <https://medicalarchives.jhmi.edu:8443/osler/aequessay.htm>

<sup>4</sup>Cannon J. Breaking & Mending: A Junior Doctor's Stories of Compassion & Burnout. Wellcome Collection, 2019.

## **“Here are the people who care for us!”**

by Dr Dan Munday,

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*Laxmi was embarrassed when she started to bleed vaginally. It was years since her periods had stopped and she could not understand why, at her age, she had started to bleed again. At first she was able to hide it from her husband. It was a long time since she had been sexually active, so this was not too difficult. However, when the sour odour started and family members began to make comments, she realised she could conceal it no longer.*

*They brought her some potions from the local medicine shop, but nothing made it any better. The family decided that her son would take her on the train to Bhopal, 8 hours away. He was used to travelling having worked as a labourer in Mumbai for several*



*years before returning to their farm. Despite being in her 60s she'd never been to such a huge city before and she was overawed by the bustle and noise. Laxmi found the hospital experience horrendous.*

*The internal examination was distressing – she'd been dreading what might happen throughout the long journey. The doctor told her that she would need an operation as there was no medicine which would help. This made her very frightened. Frightened of the unknown in a strange place. Frightened she would be left alone. Frightened that she and her family could not afford the surgery; they had nothing of value to sell. She felt such a long way from home and could not face another day of bewilderment.*

*As the days progressed, the odour became worse. Her husband and son erected a rude shelter on their land. A rush roof designed to keep the rain off the wooden pallet and straw mat on which she would sleep. It was away from the family, the other side of the buffalo house. She waited for death.*

*Laxmi could not remember how long she had languished in that out-house surrounded by flies, eating a meagre portion of the rice that her family brought to her, dozing the long days and nights away. She heard the jeep drive up and stop. Doors banged. Muffled chatter followed. Her family only came close to bring her food and they did not linger, so when the voices grew louder as they approached, her half-awake mind wondered why.*

*The woman in the blue kurta perched on the side of her pallet, speaking to her softly and gently touching her shoulder. She turned and peered into the kind eyes and confident, smiling face. "Ama, we are here to help you. Are you in pain?" She nodded. Yes, the pain. No-one had asked her about that before; she had suffered in silence.*

*It was uncomfortable to be moved as they washed her, but they were so gentle and it was a wonderful feeling to be touched in such a loving way. They gave her some medicine which did ease the pain. Slowly her family started spending more time with her. They moved her back into the house, into her own bed. Although she was weak, she could sit up a little and talk to her daughter-in-law as she cooked the rice.*

*The women in the blue kurtas visited regularly. They taught the family how to move her so that she was more comfortable. Her daughter in law was taught how to help her to wash. Neighbours started to visit, nervous at first, not staying long, but after a while they'd sit and chat, talking about what was going on in the village, especially the upcoming wedding of the tailor's daughter. So Laxmi lived until she died, free from pain, sad, but content.*

500 million people (6.5% of the world's population) live on the plains of northern India. The vast majority live in rural areas where life is hard, there are high levels of poverty and access to health care is rudimentary. It is in this area that a number of hospitals of the Emmanuel Hospitals Association (EHA) continue to provide medical services, focusing on the poor and marginalised.

Over the last 10 years an important and growing feature of EHA services has been community palliative care. Teams were established as EHA staff became aware of increasing numbers of people with advanced cancer who suffered from unrelieved pain. Local surveys revealed that many of these people were sequestered away in their homes; their families had become impoverished after purchasing expensive, but ultimately ineffective oncological treatments and having someone in the family dying from a disfiguring and feared illness brought unbearable stigma. Who would marry into such cursed families?

The only way to provide palliative care in these villages was to go out and find those in need. Supported by training from community health colleagues, the palliative care teams provide health education in villages explaining about palliative care and also making people aware of the early signs of cancer. Local people who know of those suffering from advanced illness in the community inform the team who then make themselves known to the person and their family, offering their services.

As well as providing hands on care, the teams train family members in how to provide care themselves and also work to dispel myths about cancer being infectious or an evil curse.

Through their compassionate care, those suffering from incurable illness receive symptom control and are often reintegrated back into the family and community.

What these teams achieve however is more than enabling people to live well for the short time until they die. They also save those who might otherwise have died from the effects of treatment or help those who are chronically sick and disabled to become more active and to flourish.

*Mohammed had travelled to Mumbai – a train journey of two days – to have treatment for his oral cancer. Only in his early 30s, this dreaded tumour had resulted from chewing tobacco and betel which he had been doing since his teens. The family had managed to scrape enough money together for him to have a potentially curative hemi-mandibulectomy.*

*Returning home he was too unwell to work and the family survived by his wife doing chores from house to house. The palliative care team heard about him from the imam at the local mosque and visited. They found him bed-ridden and in terrible*

*pain with an infected neck wound, being fed rice water and thin daal via a nasogastric tube.*

*The palliative care team provided treatment for his pain and infection and taught his wife to care for him and give him effective nutritious feeds through his tube. After a number of weeks Mohammed was infection and pain free. He regained his strength and the nasogastric tube was removed once was able to eat normally. After several months he had the strength resume working on his land.*

*Meena was 20 when she was crushed by a rock whilst washing clothes by the river. They struggled to remove the rock. Once free she found that she could not feel or move her legs. She was taken to the local town where they diagnosed a spinal cord injury at the district hospital and explained to her family that she would not walk again. She went home where she was bed-bound. Being resourceful and supported by her family she busied herself with sewing clothes by hand. After the palliative care team had met her they arranged for rehabilitation at the local EHA hospital where she learned to use a wheelchair. Realising her skill in sewing they provided her with a sewing machine so that she could start a tailoring business.*

These case studies illustrate how through the work of the EHA community palliative care teams, people with chronic conditions and their families have their lives transformed. The impact of such compassionate care however also has a wider effect in the communities where they operate and also for other health service providers. (1)

Low income settings such as North India are experiencing a change in disease demographics with increasing numbers of

people living with and dying from non-communicable illnesses (NCD).

The WHO over the last 10 years have recognised the importance of NCD prevention and control as the burgeoning epidemic grows. Now chronic disease management has been specifically included in the United Nations Sustainable Development Goals (SDG). SDG 3.4 aims to reduce premature death from NCDs and SDG 3.8 commits to Universal Health Coverage (UHC) by 2030.

The five elements of UHC: health promotion, disease prevention, treatment, rehabilitation and palliation are vital aspects of integrated chronic disease management and fundamental to NCD prevention and control.

The vision for prevention and control of chronic illness is essential to drive forward health care in the 21<sup>st</sup> century and to encourage individual countries to provide appropriate health services for all their citizens. However, whilst UHC is considered affordable by health economists, health services as they are currently configured in low and middle income countries (LMIC) are poorly equipped to deliver the care needed.

One important reason for this is that health care practitioners are trained to deliver an acute model of care where people attend once for treatment from which they either recover or die. With the increase in illness burden from long-term conditions health care workers need to adopt a chronic care model where repeated follow up, good communication and partnership with patients in self-management are fundamental aspects.

Whilst there needs to be a change in approach by health services, appropriate health education is also essential. People living in low-income settings are not used to attending for health screening

or in the concept of self-management for chronic illness. Traditional health beliefs also mean that people may be resistant to life-style modifications to prevent or control chronic illness.

One important 'spin off' that has been reported to result from the compassionate care delivered by palliative care teams in north India is that communities become more open to health-promotion messages and screening for disease prevention because of the confidence they have gained in the health service providers who have shown them so much care.

Community health workers have commented how palliative care has encouraged communities to engage with public health programmes. Some services are now combining health promotion and screening for NCDs with palliative care provision. People are attending and going for further investigation if necessary. Some communities are also organising with groups forming to deliver health promotion messages such as smoking cessation, dietary modification and exercise, and encouraging their neighbours to attend for screening.(2)

Health professionals too can be encouraged to develop a patient centred approach with good communication skills, problem solving and partnering with patients through exposure to and training in palliative care. An educational intervention based on these principles has been piloted in a medical school in Nepal with good results and other training programmes with health care professionals are being established.(3)

Compassionate care can be defined as proactively delivering effective interventions through developing awareness of a person's suffering and a desire to meet their need. It involves showing respect, attentive listening and tailoring treatment to take account of the person's values and context - the essence of

values-based medicine. These experiences of palliative care in low-income settings suggest that compassion lies at the root of developing appropriate health services to deliver Universal Health Coverage fit for the 21<sup>st</sup> Century.

*Acknowledgement: With thanks to Emmanuel Hospitals Association for agreeing to using their project to illustrate this chapter. All of the cases are based on previous patients but names and important details have been changed.*

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## **Self-Compassion in Primary Care: A powerful tool for patients and practitioners.**

by

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*Bruce Arroll was born in Auckland and attended Auckland Medical School 1973 to 1978. In 1981 he went to McMaster Medical School in Hamilton Ontario to do his family medicine training at the time when evidence-based medicine was starting at McMaster. He stayed in Canada for 7 years and returned to New Zealand and ultimately joined the Department of General Practice and Primary Health Care at the University of Auckland where he is now a Professor and the Head of Department. He is also a partner in Greenstone Clinic in Manurewa and has been working in Manurewa since 1991 which is a high needs part of Auckland. He is interested in brief assessment and therapy for patients with common emotional health disorders. He is the first author on the Cochrane Collaboration review on antidepressants versus placebo in primary care and a co-author of an international group examining psychological therapies in primary care.*



Offering our patients kind understanding, support, and encouragement is an undisputed foundation of primary care, and we intuitively know it works. Furthermore, during times of anxiety, vulnerability or uncertainty, the ability to extend these qualities to others or to ourselves, can prove invaluable.

However, as many people struggle with showing compassion to other adults and to themselves, it can be easier to start by thinking about the way we approach children. It is unlikely that we would criticise or shame a child for making a mistake, calling them “stupid” or “useless”, as instinctively we know that harsh criticism could reduce their capacity to think clearly, making them more anxious and less likely to risk trying again. Nonetheless, it is exactly these harsh critical phrases that can predominate our negative self-talk when we feel disappointed in our efforts or have made a mistake. Unsurprisingly, a habit of relentless self-criticism can fuel self-doubt, worried thinking and low mood. It is also not a useful method for motivating oneself, as people who have learned to tune into their positive drivers, are often more productive, and tend to have less psychological difficulties (Warren, Smeets & Neff, 2016).

This chapter will define compassion and self-compassion, and then use three clinical cases to illustrate the suitability and application of self-compassion to patients in primary care, with each of the cases exemplifying a different aspect of the approach.

### What are compassion and self-compassion?

Compassion is feeling moved in response to suffering and wanting to do something to relieve it. Self-compassion involves being caring and supportive toward ourselves when we suffer, even when our suffering stems from personal failures or perceived inadequacies (Neff & Dahm, 2014).

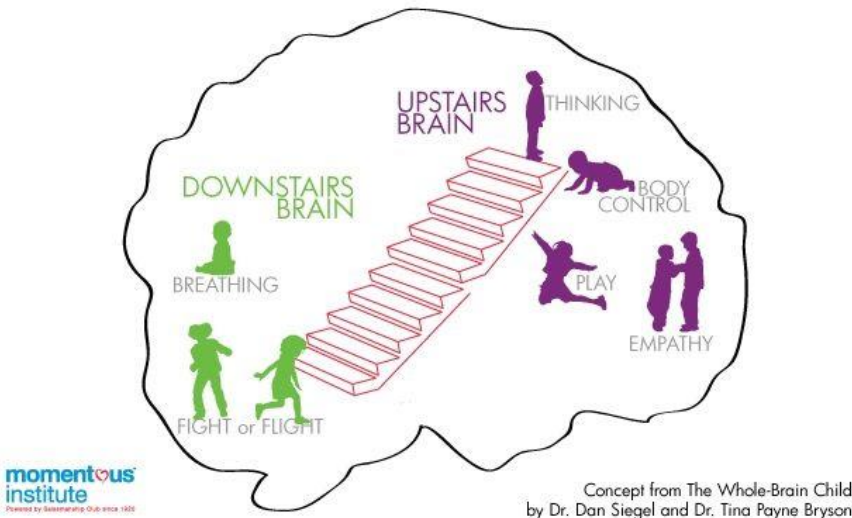
It involves framing our experiences of imperfection as a normal human experience, accepting that all people struggle in some form or another and offering ourselves the same kindness and understanding as we would extend to someone else.

Self-compassion is the logical antidote to the misery of self-criticism, which is common in our patients and also in ourselves. This does not mean we let ourselves off the hook or become passive or de-motivated, in fact, the opposite. Self-compassion creates a positive inner climate of optimism and hope with the motivation to try again.

Case 1 Barry (56 yrs): *From Self Sabotage to Self-Support: Managing Mood*

*Despite getting some benefit for his insomnia from Mirtazipine, Barry continued to struggle with low mood, and his PHQ 9 (Patient Health Questionnaire 9- a mood inventory) scores remained a concern. As a senior businessman, he had a very responsible job and although he went to the gym regularly, it had not helped his mood much. His difficulties with his family relationships had also been made worse by his low mood. Barry described an embarrassing experience in a board meeting when his mind went totally blank when asked a question he felt he been able to answer. When asked what he tended to say to himself when something like that happened, he said: "I'm such an idiot...I'm a fraud.... I should be able to know that by now."*

Figure 1: Upstairs brain, downstairs brain



When introducing the concept of self-compassion to Barry, it was explained that kindness creates safety and trust, and criticism creates an atmosphere of pressure, fear and tension. This appealed to his logic, as in his role as a manager of staff, he was naturally kind to others, yet realised that with himself, he seemed to do the opposite, and this was a factor in his low mood.

The elegant model developed by Dan Siegel (2012) of “Upstairs brain downstairs brain” (figure 1), was easy for Barry to relate to. When we are scared and tense the primitive survival brain (brainstem and limbic region) dominates and we cannot think clearly (mind going blank). When the limbic system is quiet and relaxed in response to self-compassion, we can function out of our sophisticated cortical thinking brain.

Barry found it helpful to watch some TED talks that explained how self-compassion works (see resources) and he used guided self-compassion meditation exercises to train his mind to be kinder to himself. He still has good days and bad days, but has realised that when things don’t go well he can improve matters dramatically by using his self compassion tools to relax and then he can think clearly again.

Case 2 Alexis (16 yrs) “From I’m Not Good Enough” to “I’m Doing My Best”: Managing Motivation

*Alexis came in again for exacerbation of unexplained abdominal pain, stress and anxiety. She admitted to feeling a lot of inadequacy in her social life (especially on social media) and at school. She had won a prize for her Independent Project but this had made no difference to her symptoms. Her mother had very high expectations for her and compared her to her older brother at Law School. She was slightly above normal weight for her height. When asked how she talked to herself when upset (eg after looking at social media), she stated: “It’s my fault, it’s because I am fat and such a pig around food....and lazy. If I could get off my ass and do something about it....but obviously I can’t, so it’s my own fault.”*

Diagram 2: The Perfectionist Cycle.



Diagram 2 demonstrates a common cycle whereby striving for perfection can be so intimidating that Alexis becomes avoidant of her goals. Her anxiety thus increases leading to a paralysis of her motivation and reduction in confidence. The cycle is reinforced by her internal judgement of her perceived failure to go jogging every day. Applying a lens of self-compassion to all the stages of this cycle is helpful as it creates an internal atmosphere of support, encouragement and safety.

This idea is supported in the literature as there is a positive link between self-compassion and improvement of Post Traumatic Stress Disorder symptoms in which creating an atmosphere of internal safety is central to alleviating triggering symptoms (Seligowski, Miron & Orcutt, 2014, Dahm et al, 2015). Although Alexis could see the logic of trying to be kinder to herself, she worried that if she was too “nice to herself”, she

would lose all motivation and become “even more self indulgent and lazy”. Self-compassion was a real challenge as it seemed so counter-intuitive to the way she was brought up. However, the combination of learning to accept that “things are not as I want them to be”, and kind, positive action was a more balanced and realistic goal.

Alexis found it very helpful to realise that in order to grow she had to go outside her comfort zone, “but not too much.” She discovered that instead of one big goal (eg go jogging) a series of much smaller goals was more achievable. Before bed, she tried putting her running shoes by the bed, and then in the morning “I will just put them on and go out the door” and then once out the door “I will just walk around the block”.

Many people find that if they can kindly “coax” themselves forward like this, they can more easily build up their efforts to an achievable goal of exercise.

We know that focussing on a growth mindset involving effort not outcome is a much more effective learning strategy for children (Dweck, 2007), helping them to let go of the outcome and using a process model to “do your best” and be able to reflect on what worked or didn’t work. In the same way Alexis learned to coach herself by noticing the negative self-talk and then gently saying to herself “It’s OK, I can just stick to doing my best, and fine tune my skills as I go.”

### Practicalities of Application

#### *Detecting Low Self-compassion*

The Australian and New Zealand Association for Contextual Behavioral Science recently ran webinars (<http://anzact.com/webinars/>) with presentations from each of four Acceptance Commitment Therapy (ACT) pioneers. Much of the

content was highly relevant for Primary Care. One of the founders of ACT Dr Kelly Wilson, presented a self-compassion narrative, which can be used with a person to explore whether low self-compassion might be an issue. The basis of the script was : “Imagine you are looking into the eyes of someone you love, imagine how you would be with them, what you would say to them, what you would give them etc.... Now imagine that that person is you.”

When I (BA) use this with patients, a reasonable proportion of them say they cannot do this, and in these cases, I raise the issue of problems with self-compassion. I recorded the narrative on my mobile phone, and when two patients with persisting low mood came in for a visit I played it to them and said the description reminded me of them. Both of them said yes, they were not able to show compassion towards themselves. This is what I call the “**stall button test**”.

### Case 3 Harriet (36 yrs):

*From “I’m a hopeless failure”, to “I’m only human and I can try again”:* *Managing Helpless Anxiety.*

*Harriet was a mother of 2 daughters and a gifted artist with a long history of unusual neurological symptoms (fits, twitching, buzzing and ‘brain zaps’) combined with low mood. She presented asking for a repeat of her Escitalopram and a few Diazepam which her psychiatrist suggested she uses when things get “really bad”. Her neurological symptoms (fully investigated and unexplained) followed an emotionally upsetting time when she felt she had no choice but to leave the fundamentalist church that she had been brought up in, due to existential issues that remained unresolvable. She was an anxious child and her parents and church leaders frequently ‘prayed over her’ which made her feel like a failure when things didn’t improve. She developed a very*

*rigid personality structure with an extremely hypercritical inner voice and many private fears that she was too ashamed to disclose.*

*Harriet described herself as a perfectionist, feeling crippled with high anxiety about the possibility of her neurological symptoms worsening, constantly shaming herself for her low confidence and resulting procrastination, especially in regard to her art. A vicious cycle developed and the only thing that had helped so far was Diazepam prescribed by the psychiatrist.*

Harriet tried the “Stall Test” as outlined above and found she was totally unable to express care and concern to the part of herself that was so anxious and unmotivated. She had been to positive parenting courses and so understood the importance of focussing on the process of learning rather than the outcome alone. Logically she realised that she was stuck in her self criticism and this was making her anxiety and thus also her neurological symptoms worse.

Harriet went to have some supportive counselling where initially she learned how to relax her nervous system with mindfulness exercises like slow breathing and progressive muscle relaxation. Over time her insight improved and she gradually learned to recognise her inner “critical committee member”, and she began to see how her habit of self-criticism was making everything worse. She described a new strategy of gently reminding herself that along with everyone else on the planet, she is human and has bad days sometimes. She learned to combine a simple encouraging phrase (*It's OK*), said to herself with a kind tone, alongside a compassionate gesture (holding her own hand) especially in moments when she felt uncertain, afraid or foolish. Using soothing self-touch is supported by the literature as it increases not only the vagal tone, but also raises levels of



oxytocin (Porges, 2001) both of which are calming to the nervous system.

Harriet's symptoms dramatically improved over several months to the point where she now only experiences mild symptoms approximately once a month rather than every day. She also recognised that the symptoms often correlate with stress or tension and so become valuable information, rather than something bad.

## APPLYING SELF-COMPASSION IN PRIMARY CARE

### *Presenting Mindset*

- Self blame may be the default setting
- Seldom satisfied with own efforts
- Identifying negative events as 'failure' rather than evaluating what went wrong
- Negatively comparing themselves to others
- Perfectionist
- Can present as someone who is difficult to please, blaming others and critical

### *Detecting Issues with Self-Compassion*

- Complete the Self Compassion questionnaire on [www.self-compassion.org](http://www.self-compassion.org)
- Do the "stall button" test (SEE TEXT)

### *Management*

1. Encourage patient to cultivate a voice of self-kindness in their minds.  
(Ask them if they would like a sergeant-major yelling at them in their mind or a supportive personal coach encouraging them in life).
2. Explain that this is a technique which can be learnt, which involves a 3-step thought process:
  - a. **Acknowledgement:** "This is a difficult moment.....This is stressful"

- b. **Normalising:** “Everyone has bad moments like this..... No one is perfect”
- c. **Being kind:** Saying an encouraging phrase to yourself, as you would to a friend
- 3. Refer them to exercises on Kristen Neffs website
- 4. Self soothing techniques such as using a comforting gesture eg holding own hand.
- 5. Arrange follow up

### Conclusion

No-one on this planet is perfect. Making a mistake or falling short of expectations is a human phenomenon, and how we respond when it happens has a significant impact on our well-being. Clinicians in Primary care are well positioned to notice when patients have unrealistic expectations of themselves and are overly self critical. Simple, and accessible self-compassion techniques are freely available (see resources) and can be used by clinicians and patients alike to create a more positive and supportive internal environment.

### Resources and References

Insight Timer guided meditation app: Self Compassion Teachers useful to follow:

- Kirsten Neff
- Sharon Salzberg
- Gill Fronsdal
- Tara Brach
- Also search for “Soften Soothe Allow” or self compassion etc

### Books

Kelly McGonigal *The Science of Compassion*. 2016

Kristen Neff and Christopher Germers *The Mindful Self-Compassion Workbook*. 2018

Christopher Germer *The Mindful path to Self Compassion* 2009.

Dan Siegel No Drama Discipline and Brainstorm3 Books Collection Set Paperback – 2019

(*Upstairs brain downstairs brain research and model*)

www.selfcompassion.org Kristen Neffs website with hundreds of published articles in pdf form

TED Talk on Self Compassion – Kristen Neff

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## **Servant Leadership in the Doctor-Patient Relationship**

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Conflicts of interests: we are all interested in promoting Servant Leadership (in some cases deriving direct financial advantage from it) and two of us are employed by CGL.

### **Abstract**

Coined by Robert K. Greenleaf in 1970, the term “Servant-Leadership” is a contraction of “The Servant as Leader” and is centred on the idea that the purpose of the leader of a group of people is to serve that group. This has prompted much thinking about what the purpose of leadership is and has had a profound effect on management structures. Application in

health care has so far been limited and largely confined to management, but we suggest that the rationale might be applied more widely, especially in clinical contexts.

### Introduction

After a 38-year career Robert K. Greenleaf retired from AT&T (where he worked on leadership development programmes) and went on to describe “Servant-leadership” (Greenleaf, 2002) as follows:

*“The servant-leader is servant first. It begins with the natural feeling that one wants to serve, to serve first. Then conscious choice brings one to aspire to lead. The difference manifests itself in the care taken by the servant-first to make sure that other people’s highest priority needs are being served. The best test, and difficult to administer, is: Do those served grow as persons? Do they, while being served, become healthier, wiser, freer, more autonomous, more likely themselves to become servants? And what is the effect on the least privileged in society; will they benefit or, at least, not be further deprived?”*

Although his ideas were anticipated as far back as 600 BC by Lao Tse, who wrote “...The best ruler stays in the background, and his voice is rarely heard.

When he accomplishes his tasks, and things go well, The people declare: It was we who did it by ourselves.” (Seddon, 2018). It is only since the 1970s that a movement has been developing throughout the world to promote Servant-leadership (including at the largely virtual UK Greenleaf Centre - see References for contact details), but organisations elsewhere have based themselves on similar ideas - for example the Buurtzorg Nederland (home care provider) model for district nursing founded in the Netherlands in 2006/07 (Royal College of Nursing Policy and International Department, Policy Briefing 02/15, 2016).

The idea of helping others selflessly does not come easily to everyone, but many people do not shy away from the idea and the valuable contribution of people that are willing to subjugate their own wishes to serve a larger plan is increasingly being recognised. At the same time, recognition that authority which is too forcefully implemented can have a stifling effect on employees has led to many attempts to flatten the “hierarchical pyramid” (as discussed, for example, by Edwin Ghiselli and Jacob Siegel [Ghiselli and Siegel, 1972]).

It is recognised in the business world that an important part of leadership is encouraging people in order to bring out the best in them (Lagarde, 2019) but, Medicine has been slow to adopt this. In recent times, however, many medical professionals are beginning to embrace the idea.

### What is Servant Leadership?

Servant-Leadership is about serving a group of people and leading them at the same time (McNerney, 2012); ten characteristics that exemplify it have been suggested by Larry Spears (Spears, 2010): listening, empathy, healing, awareness, persuasion, conceptualization, foresight, stewardship, commitment to the growth of people and building community.

There is significant overlap, but the ones that are, perhaps, most pertinent to the health professions are listening (the start of a healing relationship), empathy (which is helped enormously when relative “status” in the consultation is disregarded), healing (“Many people have broken spirits and have suffered from a variety of emotional hurts...servant leaders recognize that they have an opportunity to help make whole those with whom they come in contact”) and persuasion (convincing others, rather than coercing them into compliance).

The practitioner of Servant-leadership needs to act both as leader (for example presenting clinical treatment options) and as servant (prioritising patients' wants). Often criticised as a soft skill, there are times when firmness and clarity need to be demonstrated and boundaries set very clearly. Mutual respect is central and respect for oneself critical if one is to avoid "compassion fatigue" [Tee 2018]).

Helping patients relax facilitates clinical interview and many techniques can be used. Shaking hands and using both first and second names when introducing oneself are good ways of showing respect (although the expectations of different cultures needs to be respected) while paying careful attention to the precise wording that a patient uses ("active listening", Rogers and Farson, 1957) is vital. All interactions should be honest and open – and "genuineness" can greatly facilitate the development of trust. Extra effort (and time) may be required, but establishing good rapport and taking decisions jointly allows for better and more effective treatment plans to be developed.

It is worth mentioning that use of the term "servant" suggests subservience to some people and is not liked; recommending that they think of attending to patients as a way of serving a divine or naturalistic being, rather than being subservient to another human being, may be helpful to them.

### How can Servant-leadership be implemented in the Clinical Consultation?

In the clinical environment health practitioners have sometimes been guilty of distancing themselves from their patients and adopting a matriarchal/patriarchal stance. Although greater knowledge and experience are generally associated with better clinical decision-making and patient outcomes (which makes this approach very understandable) this approach sometimes appears to have been defended more fiercely than it should have been.

Historical precedence is important, but such thinking can be flawed and, especially in a clinical consultation, ignoring the views of patients may result in inappropriate treatments being offered. Persuasion is often the best course of action and discussing how to proceed *with* the patient has been shown to significantly aid compliance (Baumann and Trincard, 2002, Storm et al, 2008) - thereby promoting safety. Furthermore, as Rodger Charlton states (Charlton 2015) true professionalism should include compassion (the genuine wish to relieve suffering). In recent years this appears to have become relatively scarce and to have lost ground to training in administrative or computing skills and Evidence Based Medicine.

Greater knowledge has often been used to command authority but, in the clinical environment, the best solutions usually combine information held by the healthcare worker (received wisdom and practical experience) and the patient (understanding of and familiarity with their personal situation) - as proposed by David Tuckett (Tuckett et al, 1985).

### Clinical Experience

Effective leadership in the National Health Service (NHS) has often seemed to be lacking and, while there are a plethora of tailor-made courses offering to teach good leadership, being a follower remains less appealing (Kar, 2019). There often seems to be a desperate scramble to become “*the leader*”, but it is slowly being appreciated that there can easily be “too many cooks in the kitchen”!

Notwithstanding, Servant Leadership is slowly being adopted in Medicine, particularly in disciplines relating to mental health, such as Addiction Psychiatry (where hitherto its application has been largely confined to staff management). Equitable working with patients has long been recommended by the GMC (GMC, 2008) and large organisations



such as Change, Grow, Live (CGL) have been increasingly focussed on staff feedback, for example through holding dedicated “Regional Assemblies” when management and clinical staff pool their ideas. The one held in 2019 (attended by over 700 people) concluded that managers should spend more time shadowing staff on the front-line in order to obtain greater insight into the practical difficulties that apply when implementing ideas that seemed good in theory - possibly on a regular and on-going basis.

### The Way Forwards

Today there is less deference to authority than in the past and there are undoubtedly some advantages to this. Greater experience generally makes for better clinical decisions (especially when these are not straightforward) but acknowledging the views and opinions of patients usually results in better management plans being made (and adhered to) - although there are occasions when shared decision-making is not appropriate (for example in the emergency situations referred to by Deegan and Drake, 2006).

There is a growing consensus that attending to and prioritising patients’ wants should be the default position and this is slowly permeating healthcare institutions everywhere. Large organisations such as Change Grow Live certainly appreciate the wisdom of this and, increasingly, health professionals are employing it in their interactions with patients.

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## **Many Names, One Heart.**

by Katie Reginato Cascamo

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Society is aching for new ways of leading organizations. Healthcare professionals often search for paradigms, theories, and suggestions to lead themselves better, their communities better, and those who come to them—for better care. There seems to be a temptation in each of us that if we assign ourselves to one particular philosophy of healthcare leadership, we are strengthened by this singular paradigm. I will suggest in this chapter that as we discover new realms of compassionate, caring leadership, that we find the courage to look beyond the leadership or paradigm title for shared values. The discovery of shared values invites healthcare professionals to include highly credible, new stakeholders to healthcare such as non-clinical partners with lived healthcare experience.

To ground my decade-long work in leadership studies, let me share a story where compassionate healthcare providers invited me into a world of healthcare renewal. Ten years ago, my life shifted dramatically with the very early term birth of my son at

1131 grams (2lbs 8 oz). Originally from San Francisco, I did not conceptualize the difference between rural and urban healthcare when I relocated away 535 kilometers from the city center. This difference became apparent when I received an H1N1 diagnosis at 26-weeks' gestation from an urgent care center and was told to avoid the community hospital at all costs. Three weeks later, I developed pre-eclampsia that quickly became critical at 29-weeks' gestation. The diagnosis of pre-eclampsia with 155/115 blood pressure led to being critically airlifted through a blizzard at -18 degrees C.

This lived experience introduced me to healthcare providers with low-emotional intelligence and poor teamwork – it created fear and distrust in me as a patient. This crisis also introduced me to providers whose feelings of joy and abundance in patient care forever transformed my life and my call to serve the world.

The cornerstone of healthcare for many providers is empathetic, compassionate patient care (Dierendonck & Patterson, 2014). The narrative of healthcare providers healing people and altruistic purpose often supersedes the challenges posed by healthcare systems. Every country approaches the healthcare system differently with many sharing similar organizational challenges. In the United Kingdom, one-third of healthcare providers reported feelings of burnout. In the United States, almost half of healthcare providers reported feelings of burnout. One temptation with data, where one country's burnout rate is higher than another, is to think *we're not that bad*. Listen to the stories of a physician who is experiencing feelings of burnout, cynicism, or has had suicide ideation and that percentile difference takes on new meaning. Stories and relationships are powerful to making meaning of data, though they do not always tell the whole story.

Stories offer listeners an opportunity to glimpse inside the struggle providers face, but simultaneously offer a pathway for others understand and share empathy with this important audience.

Two years after my lived healthcare experience I discovered Servant-Leadership. Reading the words of Robert K. Greenleaf activated excitement in my heart as I tried to make sense of my own healthcare journey (Greenleaf & Spears, 2002). Greenleaf writes, *“The servant-leader is servant first. It begins with the natural feeling that one wants to serve. Then conscious choice brings one to aspire to lead. The best test is: do those served grow as persons: do they, while being served, become healthier, wiser, freer, more autonomous, more likely themselves to become servants? And, what is the effect on the least privileged in society; will they benefit, or, at least, not be further deprived?”* (Greenleaf & Spears, 2002). Servant-Leadership is a robust leadership paradigm that invites leaders to reconstruct our old paradigm of top-down leadership to one that invites shared decision-making at all levels of the organization (Spears & Lawrence, 2004).

This inversion in the way we lead people from the positional authority to persuasion redefines our conceptualization of leadership (Spears & Lawrence, 2004). Servant-Leadership attracted my interest through my lived experience. One of my most trustworthy, key compassionate caregivers served as the housekeeper (cleaner). Trained in Trauma Informed Care, the relationship I built with this servant-leader felt less clinical (Coughlin, 2017). Sharing stories about my baby and emotions around a NICU (Neonatal Intensive Care Unit) stay felt more sacred. I later learned she communicated with our nursing staff and social workers as part of well-rounded clinical care team. This later knowledge increased my gratitude for the healthcare system whose foresight saw natural relationships between patients and staff.

The strength of Servant-Leadership in healthcare emerges from an emphasis on person-centered care. As we re-imagine our knowledge of leadership, we transform the heart of what it means to be a compassionate healthcare leader. As we focus on serving other people above ourselves, many people rediscover their purpose for healthcare. And it's this renewable resource that becomes a virtuous cycle.

Larry Spears, President & CEO of The Spears Center for Servant-Leadership, Inc. and former CEO of the Greenleaf Center built on Greenleaf's work through his "Ten Characteristics of Servant-Leadership" that include: Listening, Empathy, Healing, Awareness, Persuasion, Conceptualization, Foresight, Stewardship, Commitment to the Growth of People and Building Community (Spears & Lawrence, 2004). Spears invites us to lead with these practices not solely as action or process rather an opportunity to be in relationship with the people we lead. As we practice these characteristics of Servant-Leadership, compassion naturally results in healing for ourselves and our relationships with other people.

Compassionate forms of leadership share many of the same characteristics as Servant-Leadership. Both emphasize shifting the prevalent dehumanizing individualistic model to one that facilitates the growth, development, and well-being of people within organizations and society (Zulueta, 2015)

The shared values between heart-centered forms of leadership offer us an opportunity to see patient care through a new lens. Stories abound of providers who accept and promote patient-care processes without the interior heart transformation. This adherence to the philosophy without the deeper, reflective action turns away the very people who would co-create a new way of

imagining our healthcare systems through a more holistic approach.

A global movement emerged in the last 20 years that shares many of the values of compassionate Servant-Leadership and person-centered care practices. Now enveloped under the organizational collective, The Presencing Institute, this global movement spans 180 countries, strengthens this heart-centered, transformative work through shifts in consciousness and emphasis on healing the heart of our societies (*The Presencing Institute* 2020). Their work activates many of the same organizational shifts to more humanistic approaches to patient care.

As a non-clinical partner with lived experience in the healthcare realm, the first step to embracing new approaches to healthcare is to invite a professional with lived experience to your healthcare team. Our non-clinical role improves patient perception of the bedside care and often improves healthcare outcomes. Seek opportunities to attend conferences and trainings with workshops and keynotes from patient partners or patient and family advisors. We are increasing in value as healthcare systems expect providers to do more with less. We are trained to streamline costs and are equipped to listen empathetically in a way that strings together lived experience and professional credibility.

Most importantly, nurture yourself in times of exhaustion and burnout. Show yourself the same compassionate care you give to patients. Through this we sense and feel your commitment to us as patients.



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## **Compassion in the Community.**

### **BrumYODO: A community-led palliative care initiative. Why do people attend and what are the benefits?**

**by Sarah Mitchell**

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#### **Introduction**

An increasing number of people, both old and young, are living with complex, incurable healthcare conditions and multi-morbidity. These conditions are unpredictable and associated with sudden health deteriorations, resulting in admission to hospital, and a risk of death. People experience a wide range of physical symptoms due to their conditions, and there is often an immense emotional burden for those living with the conditions, their family members, carers and friends.

Palliative care is an approach to care advocated for anyone living with a life-threatening condition, focussed on improving quality of life through

the timely identification, assessment and management of physical, psychological, social and spiritual need.

However, significant inequalities exist in the provision of palliative care. Statutory funding for specialist palliative care services is inconsistent; such services rely on charitable donations and currently lack the resource and capacity to provide palliative care for all who could benefit. People with cancer are more likely to receive specialist palliative care than those with non-malignant conditions(1).

General practitioners, primary care and community nursing teams have an important role in the provision of palliative care, however large numbers of people do not have their palliative care needs identified and are not included on general practice palliative care registers (2). The situation is compounded by primary care services experiencing increasing workload pressures. Barriers to the provision of palliative care in primary care include a lack of time with patients, conflicting clinical, administrative and managerial demands, compromised continuity of care (including out of hours), and depleted community nursing services (3).

There is a pressing need to improve the delivery of palliative care to the increasing number of people who could benefit from it. The limitations of relying on overstretched healthcare services have been recognised, with a call to focus efforts on increasing innovative, population-based, public health approaches (4). A diverse range of public health palliative care initiatives exist around the world; some are community led while others are led and co-ordinated by an organisation, frequently a hospice or other specialist palliative care provider (4).

Compassionate Communities, the Dying Well Community Charter (5,6) and Compassionate Cities (7) are all examples from the UK.

Currently the published literature regarding the impact of public health palliative care approaches is limited (4). The existing evidence is mainly focussed on projects led by healthcare organisations; few papers describe the impact of naturally occurring social networks (8-10). This may in part be due to the significant methodological challenges in evaluating the impact of a community-led approach.

BrumYODO (Birmingham, You Only Die Once) is a community-led initiative, committed to raising awareness of matters related to death and dying by encouraging more open and honest conversations. This chapter describes how BrumYODO was developed, and the results of an evaluation carried out at the 2017 BrumYODO festival, A Matter of Life and Death.

### BrumYODO

BrumYODO is a grassroots community collaborative, that was conceptualised and founded in 2015, with conversations between a number of people living in Kings Heath, Birmingham, including undertakers, artists, florists, specialist palliative care professionals, hospice workers, GPs and several others.

Together, the group organised a marketplace event in Kings Heath village square during Dying Matters Awareness Week. Local hospices, hospitals, artists, florists, undertakers and funeral transport organisations hosted stalls, and there were other interactive elements to the marketplace including a “Before I Die” board. Members of the public passing by engaged with the event, with many seeking advice and guidance about specific issues related to death and dying. Some stopped to share personal experiences with those hosting stalls. The event drew local interest, both at the event and through social media.

Following this first event in 2015, the BrumYODO collaborative continued to grow. In 2016, the group organised a series of events across the city for Dying Matters Awareness Week, including Before I Die Walls, Death Cafés, and a pop-up shop. Since 2016, a variety of events have been organised by BrumYODO during subsequent Dying Matters Awareness weeks and at other times of the year, including Death Café's, Death over Dinner events, Death Discos and events at schools and faith organisations.

BrumYODO was awarded runner up in the Most Innovative Death Public Engagement Event at the 2016 National Funeral Awards, and was joint winner of the Dying Matters Awareness Initiative of the Year Category at the National Council for Palliative Care 25th Anniversary Awards in 2016.

#### The “A Matter of Life and Death” Festival.

During Dying Matters Awareness Week 2017, BrumYODO organised its first weeklong festival of events in Birmingham entitled “A Matter of Life and Death - everything you wanted to know about death and dying but were afraid to ask”. A successful bid to the Arts Council for funding allowed a member of BrumYODO to manage the festival, and partnerships were formed with the Midlands Art Centre (MAC) and Birmingham Museum and Art Gallery, who agreed not only to host events but also to assist with the promotion and administration of the festival.

The festival has run annually since 2017, during Dying Matters Awareness Week. A full programme of events is organised each year at a variety of venues across Birmingham. These events have included trips to a natural burial ground and a crematorium, practical workshops including advice on how to plan a funeral, multi-cultural panel talks and debates, theatre shows and

performances for both adults and children, and photography exhibitions.

Workshops have also taken place including life drawing and an exploration of food and death customs. Tickets were sold for some events, while others were free to attend on a “drop-in” basis. A series of creative workshops took place in the run up to the festival, including arts projects at local hospices and schools, and artwork from those workshops displayed during the festival at the MAC. Photograph 1 shows the printed festival programme from 2017.

Photograph 1: Printed programme of events



The 2017 festival also included a weekend marketplace at the MAC featuring a variety of stalls (Photograph 2). Stalls were hosted by local hospices, who provided information about their services, and artists, undertakers and florists displaying their work.

Photograph 2: “A Matter of Life and Death Festival” marketplace 2017



Featured at the marketplace event was a woodland artwork experience, where participants could hire a headset and lie down in the woodland at Cannon Hill Park, where they could listen to an audio recording that described the biological and chemical processes that occur in the body after death (11). There were also displays of coffins, ornaments, floral displays and an “Infinity” burial suit (the first imported into the UK) (Photographs 3 and 4). An Infinity burial suit is worn by the deceased after death, and contains thread infused with mushroom spores. After burial, mushrooms assist with decomposition of the body, essentially resulting in the body being turned into compost. The suit provides a more environmentally friendly option for burial than more traditional methods of burial or cremation (12).

Photograph 3: Wicker coffin and floral arrangement on display



Photograph 4: Infinity burial suit on display



### **Evaluating “A Matter of Life and Death”**

Little is known about how many people engage with Compassionate Community initiatives, who they are, why they engage, or what the potential benefits may be. An evaluation was attempted using a number of different methods to gather



information during that first festival in 2017. The next section of this chapter outlines the methods that were employed and the findings of the evaluation.

The evaluation aimed to address the following questions:

- How many people engaged with the “A Matter of Life and Death” festival?
- Who attended the “A Matter of Life and Death” festival?
- Why did people attend the festival?
- What did they describe as the benefits?

### Conducting the evaluation

The festival was a public event with a wide range of events, so consistent methods of collecting data were almost impossible. A pragmatic approach was taken, with data collected using methods that were chosen based on their feasibility. The aim was to collect both quantitative and qualitative data, and to triangulate this data in order to compensate for the strengths and weaknesses of each method. Data was collected using paper and online surveys, voting boxes at the event, and by interrogating social media statistics.

## **1. Surveys**

Three surveys were conducted as follows:

- Survey One: Gathered demographic and experiential data from participants at the five pre-festival creative workshops.
- Survey Two: An opportunistic on-site paper survey with people who attended each of the festival events.
- Survey Three: An online post-festival survey, distributed via email to everyone on the BrumYODO email list.

BrumYODO members, using previous surveys carried out to evaluate arts events, devised the survey instruments. They were not validated.

SurveyMonkey was used to collate the data from all three surveys. Quantitative data was analysed using descriptive statistics. All free text comments were entered into qualitative data management software, NVivo, and a thematic content analysis was conducted using the principles described by Braun and Clarke (13).

## 2. Voting boxes

A voting box, shown in photograph 5, that had been used at previous community engagement events in Birmingham (14) was used to ask people to respond to the statement "I feel comfortable talking about death", with "yes", "no" or "neutral" as possible responses. The box counted the numbers of responses to each, but did not enable capture of any other data about the people who provided the responses.

Photograph 5: Voting box



## 3. Electronic counting devices and social media statistics

Information was gathered from a number of sources to try to estimate the number of people who engaged in some way with

the festival. The number of people who had been reached by the festival was estimated using data including footfall, ticket sales, social media statistics, email list subscribers and survey response rates. Footfall at the MAC was estimated using an electronic counting device at the door of the MAC. Records were kept of ticket sales. Twitter statistics were collected for @BrumYODO (15). People were asked to sign up to the BrumYODO email list throughout the week, and a diary was kept of all regional and national press coverage that occurred in relation to the festival.

### Results

How many people engaged with “A Matter of Life and Death” festival?

Data from the electronic counting device was available for each day of the festival. Estimates for the MAC footfall during May 2017 was 3,816 per day, although not all of those people would have been attending the festival as there were other events taking place at the centre at the same time. The prominent, central location of the festival events at the MAC meant that all of these people would have had the opportunity to see exhibitions or the marketplace event that took place. A total of 612 tickets were sold for the 38 ticketed events which took place during the week. On Twitter, @BrumYODO made 74,011 impressions, 1,969 engagements and 394 likes during May 2017. The Facebook page attracted 90 new followers and the BrumYODO email distribution list grew from 83 people in March 2017, to 165 by the end of May 2017. Wider reach was achieved through interviews on two local radio stations and articles in three local newspapers and magazines. Nationally, the “i” newspaper ran a half-page feature about the festival.

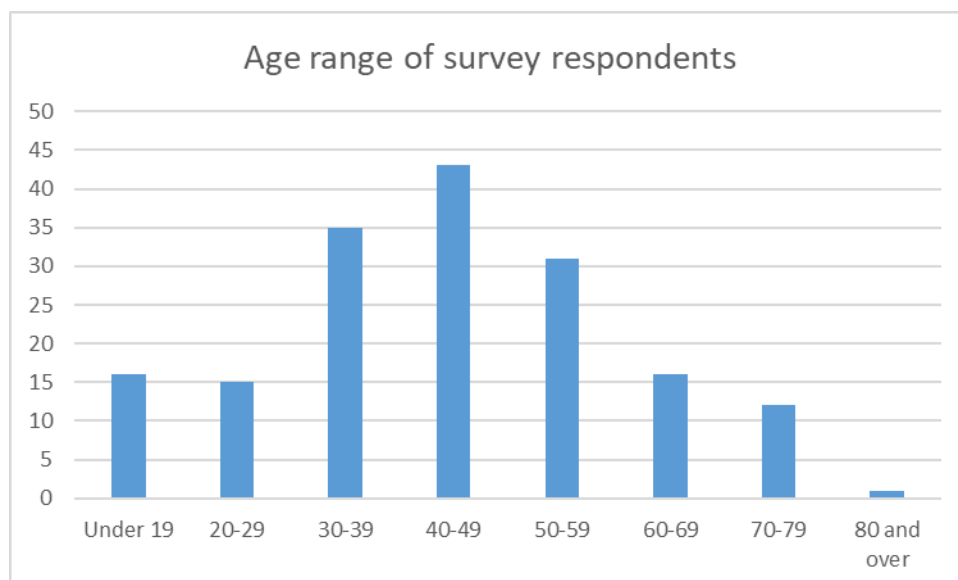
There were 47 responses to Survey One. This represented a 100% response rate amongst participants of the pre-festival workshops. 125 responses were collected for Survey Two during

the festival. Survey Three was sent via email to 165 people, but only 15 responded (0.09%).

### Who attended the “A Matter of Life and Death” Festival?

Demographic data was collated from all three surveys. 169 people provided data regarding their age. Results are outlined in figure 1. The majority of people who attended the events were aged between 30 and 60 years. People under the age of 19 years, including children, also attended the event.

*Figure 1: Ages of people who attended the “A Matter of Life and Death Festival” 2017*



145 responses were provided regarding gender. 33 (21%) were male, 111 (77%) were female and three (2%) identified themselves as non-binary. 78 respondents provided information about their ethnicity, of which 51 (65%) were White British or Irish, three (4%) were Mixed Race, 18 (23%) were Black African or Caribbean, and six (8%) were Asian Indian, Bangladeshi or Pakistani.

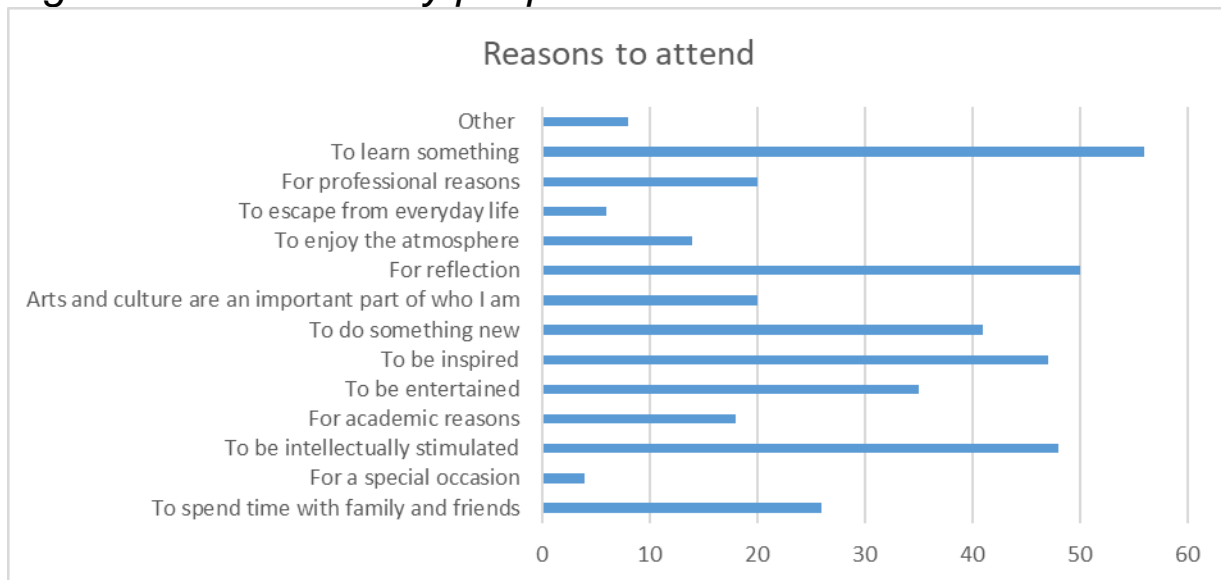
50 (40%) were visiting the festival alone and 74 (60%) were with others. 88 (72%) were visiting a BrumYODO event for the first time, 34 (39%) had been to a previous BrumYODO event.

The voting box attracted 97 responses. 33 (34%) replied “Yes” to the statement “I feel comfortable talking about death and dying). 36 responses were “neutral” (37%), 28 were “no” (29%).

Why did people attend the festival?

Reasons to attend the festival were varied. Respondents were invited to give as many reasons as they wished to from the list outlined in figure 2. The most commonly selected reasons were “to learn something”, “to reflect” and “to be intellectually stimulated”. Amongst participants who selected “other”, free text responses included “to consider something”, “death is part of life, not morbid” and “to have a greater understanding of the funeral process”.

*Figure 2: Reasons why people attended the festival*



## What were the benefits of attending the event?

Thematic analysis of the qualitative data from the surveys resulted in two overarching broad themes, providing insights into the potential benefits of attending the festival, as follows:

1. A feeling of engagement and personal benefits, and
2. A choice of events and opportunities for learning.

### 1. A feeling of engagement and personal benefit

Over 50 comments could be categorised as personal feelings. Many were thank-yous to BrumYODO for organising the festival. Others positive comments included “overwhelming!!”, “very moving!”, “well done, want to see more”, and “brilliant programming”. A level of engagement was implied through comments such as “really glad I came and got involved” and “looking forward to getting more involved next year”. Other examples where the benefits of being able to discuss death and dying, including personal experiences of bereavement, are illustrated in the quotes below:

*“Welcoming, thought provoking, compassionate. An opportunity to explore and ask those questions that we often avoid. Thank you for organising an event to allow people to explore the issues that surround death.”* (respondent, post-event online survey)

*“Nice friendly environment expressing our thoughts through art. Feeling safe and able to converse about lost loved ones fondly.”* (participant in pre-festival workshop)

Comments from the surveys that specifically related to feelings about death and dying all demonstrated a desire amongst respondents to talk more openly about death and dying in the future, with a wish that this was a more widely recognised issue in society. Survey comments indicated that visitors to the festival

had either started to have those conversations, or planned to talk to others following their experience of the festival. Three examples are provided below:

*“I think talking about dying is as important as talking about living. After all, we do both!”* (participant in pre-festival workshop)

*“Most of all it reassured me that thinking about death is important on an individual, familial and societal level - and that's the starting point for many of the conversations I've been having subsequently.”* (respondent, post-event online survey)

*“I think this was an excellent festival and wish there were more like it more regularly because as a society we don't talk about these issues enough. I like that the people running the events were open, funny and empathetic.”* (respondent, post-event online survey)

## 2. Choice of events and opportunities for learning

Many positive comments were received about the diverse range and choice of events for people to attend. One respondent wondered suggested a “coffin loyalty card” because she attended so many different events during the festival, but was unsure what kind of benefit such a loyalty card would result in:

*“I went to so many events that I found myself joking about what a loyalty card might reward me with ... coffin not coffee?”* (respondent, post-event online survey)

There were also many examples of learning amongst the survey responses. Respondents described specific opportunities to learn new things including the following:

*“A really interesting talk about the history and associations of food with funerals and amazing food”* (paper survey response, F aged 40-44yrs)

*“Very interesting topic. I am shocked they pump chemicals in you to be buried”* (paper survey response, F aged 10-24yrs)

### Negative comments

Negative comments were infrequent and tended to relate to more general concerns such as the comfort of the seats in the cinema, or the quality of audio equipment in one of the panel talks.

### Discussion

This evaluation provides an insight into the experiences of members of the public who attended a community-led public health palliative care initiative, the BrumYODO “A Matter of Life and Death” Festival. The insights are useful but are limited due to the data collection methods, which were feasible and allowed for in-depth data to be gathered from a large number of participants, but lacked scientific rigor. The response rate for the surveys was low when compared to the footfall and ticket sales statistics for the festival.

All of the data collection methods such as surveys and voting boxes were carried out only once; a more detailed insight into the impact of the festival could have been gathered by asking those who attended to complete surveys before and after events. Other limitations and challenges include likely feedback duplication (with some people responding to more than one survey), and sampling bias; the paper evaluation forms were widely available, but the ticketed events where people were sitting down and could be provided with the surveys and pens to complete them, were most conducive to form filling.



### Festival visitors

Survey results suggest that most visitors to the festival were women, most were aged between 30 and 60 years and most were White British. This is not representative of the local population of Birmingham (16), so if these results are representative of who attended the festival (rather than being representative of those who took part in the evaluation), there is more work to be done to attract a more diverse audience, particularly in a diverse and multicultural city such as Birmingham.

70% of respondents were visiting a BrumYODO event for the first time. This is encouraging and could be attributed either to the type of events that the festival provided or to the central, high profile venue.

The footfall estimates for the MAC were much higher than either the ticket sales or participants in feedback surveys; it is only possible to speculate about how many of these people engaged with the festival opportunistically, or whether the festival had any impact on them in terms of their views and behaviours. Social media statistics provided some evidence to suggest that engaging with the festival in a virtual space was popular, both with Twitter and Facebook.

### Potential benefits of attending the festival

One of the aims of the festival was to create welcoming space for people to consider and talk about issues related to death and dying. The survey responses indicated that people who attended the festival had valued the opportunity for both personal reflection and learning. There were comments about enjoying events, feeling “overwhelmed” and “moved”, with respondents stating that they felt more empowered to have conversations with loved ones about death and dying as a result of attending the festival.

The environment of the event, and the approach of those who were hosting the events are both likely to have had an influence on whether people felt able to engage or not. The events were almost entirely hosted by volunteers, including those who were members of the BrumYODO organising committee, who were likely to be highly motivated and engaged in the palliative care and Compassionate Community agenda, for different reasons depending on their professional background. All survey respondents said they would recommend the festival to others.

Survey comments indicated that respondents planned to discuss death, dying and bereavement with others following their experience of the festival. This is an important finding, indicating that a festival of this nature provides a way to meet the aims of BrumYODO and Compassionate Communities initiatives more widely, promoting open conversation and community support for those facing death and bereavement.

Social media statistics suggested that high numbers of people engaged with the festival in a virtual way. This is an interesting finding, possibly suggesting that social media and online platforms provide a space for people to express their thoughts and feelings about death and dying, which may be less daunting than talking about these issues face to face.

### Conclusion

BrumYODO is a grassroots organisation setting out to meet the needs of its own community. This approach has its challenges and opportunities being outside of traditional organisations associated with death and dying. The “A Matter of Life and Death” Festival was a novel approach moving conversations about death and dying away from a healthcare professional focus towards an approach which is led by the community and incorporates strong

creative elements, viewing the acknowledgement of death and dying as an essential aspect of wellbeing in life.

### Acknowledgements

This chapter is presented on behalf of the BrumYODO collaborative. SM would like to acknowledge all who organise, attend and take part in BrumYODO events.

### A summary of learning points from the organisation and evaluation of the festival, to assist with the planning of future events:

#### 1. *Promoting the festival and reaching a wide audience*

The “A Matter of Life and Death” festival benefitted from partnerships with high profile arts organisations in Birmingham (the Midlands Arts Centre (MAC) and Birmingham Museum and Art Gallery). These two central locations for the events probably enhanced attendance at the festival, and allowed for wider engagement, with visitors to the venues for other events engaging with the festival events opportunistically.

The use of social media and online platforms provided a method to engage widely with many people. This was also a useful way to promote the festival and events, although other methods including posters and printed programmes were also helpful. Time is important in order to ensure adequate publicity, particularly if there are ticketed events.

The survey results suggest that the diversity of those attending the festival was not representative of the cultural and religious diversity of the city. Recruiting a diverse organising committee could support the reach of activities, as well as more involvement of faith and cultural organisations. Building on the feedback obtained during this evaluation that respondents valued the opportunity to learn, events promoting learning about differing cultural beliefs in death and dying may be attractive.

## 2. *Promoting conversations about death and dying*

The festival made use of community arts venues, which appeared to be ideal for approaching conversations about death and dying in creative ways. Organisers and presenters who were willing to have informal conversations contributed to the welcoming feel of the festival environment were also important.

## 3. *Discussion of death and dying on social media*

There was significant engagement with the festival via social media. Further understanding into this would be helpful. It is possible that the online space for conversations is more acceptable or accessible for some than face-to-face conversations about death and dying. This has potential implications for healthcare service delivery and care planning in the future.

## 4. *Conducting future evaluations*

More information is needed to inform the development and growth of Compassionate Communities in the future. This evaluation was challenging to conduct, but provides useful insights which are of immediate relevance to others intending to organise similar events. Where possible, before and after surveys have the potential to evaluate the impact of attending a festival event on an individual.

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