



Welcome to the 2012 summer issue of the BPOS newsletter.

This issue contains a special feature on the book *The Other Side* by Dr Kate Granger, an Elderly Medicine Registrar in Yorkshire. *The Other Side* tells the story of Kate's journey as a patient coming to terms with a terminal cancer diagnosis. This newsletter contains three reviews of Kate's book (by a medical student, an SpR in palliative medicine and a senior lecturer in cancer and palliative care) and a Questions-&-Answers feature with Kate, as well as two short excerpts from Kate's new forthcoming book *The Bright Side*.

This issue also sees the beginning of a new regular feature: 'PhD student spotlight'. In this issue's spotlight, Dawn Doran from the University of Central Lancashire tells us about her PhD research into the experiences of gay men with prostate cancer. We also have student reviews of the recent 'Surviving the Psychosocial Oncology PhD' event at the University of Chester. Thank you to all our newsletter contributors.

You will have noticed that this issue of the newsletter has arrived in your e-mail inbox rather than through your letter box. At the last BPOS executive committee meeting in June, for financial and environmental reasons, a decision was made to move to an electronic only newsletter. However, please do let us know your thoughts and feedback on this decision, as it will be reviewed before production of the next issue.

If you would like to contribute an article to the newsletter, please do get in touch. Articles might be reports of studies in progress, reports of preliminary research findings, brief literature reviews, explorations of relevant methodological or ethical issues, conference reviews or book reviews. If you have something that you'd like to contribute, please contact me to discuss your ideas. The deadline for content for the next edition will be 31st January 2013.

I hope you enjoy this issue.

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The Other Side by Dr Kate Granger

In the words of author Dr Kate Granger, *The Other Side* is "a true story of one doctor's journey as a patient coming to terms with a terminal cancer diagnosis".

The hope is that healthcare professionals will read it, in particular young doctors and medical students, and understand exactly what being a patient is really like and how their behaviours, no matter how small can impact massively on their patients. It is also a story of personal battles with control and learning how and when to relinquish it.

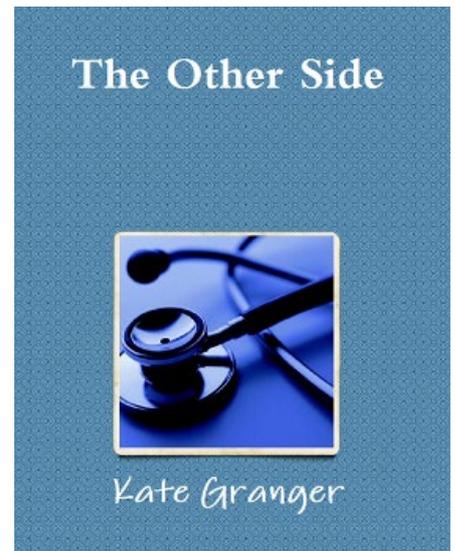
This issue of the newsletter features three reviews of Kate's book: from James Gupta, a first year medical student, from Jennifer Klimiuk, an SpR in Palliative Medicine, and from Anne Arber, a Senior Lecturer in Cancer and Palliative Care. There is also a Questions-&-Answers feature with Kate, as well as excerpts from Kate's new forthcoming book *The Bright Side*.

Review of *The Other Side* by James Gupta, medical student

There is no shortage of books on cancer. Amazon even gives it its own category boasting over 11, 000 different books. In spite of this, '*The Other Side*' stands out as one that is remarkably honest, personal and especially to healthcare professionals – important.

Whilst it discusses themes that are certainly of interest to the wider public, it is definitely aimed towards a more professional audience. However, it should be pointed out that it is not by any standards 'difficult reading' – the many themes and potentially practice-changing messages of the book are woven seamlessly into an almost diary style narrative of Dr. Granger's (Kate's) experiences.

One recurrent theme in the book that illustrates this is ordering tests that may not be absolutely necessary. An elderly medicine registrar, Kate describes herself as a 'conservative physician' which I strongly believe is something to aspire to, especially in a time when more and more procedures, tests and scans are being driven by physician, rather than patient



demand. Below is an excerpt from the book where Kate describes her first experience of an MRI scanner:

"I am feeling really petrified now and shut my eyes tight. I decide I will not be opening them again until the scan is completed. I grip the buzzer and try to concentrate on my breathing which has become uncontrollably rapid and erratic"

And even after the scan is completed:

"I am a total wreck and daren't open my eyes... ...I keep telling myself it's over but the internal scared feeling stays with me all day"

The take-home message here is clear to any healthcare professional who has ordered a test. Modern technology and the changing roles in healthcare means that for doctors, ordering a test is often a matter of signing a form or clicking a button, waiting for a bit and then receiving the results. This process, whilst efficient and beneficial in many ways, comes with the huge drawback that we do not experience the 'middle bit' between ordering the test and receiving the result: it blinds us to the often disrupting and potentially traumatising effects that tests can have on patients. I personally believe »

that this is one of the major sources of communication breakdown between doctors and patients.

As a first year medical student studying at Leeds, where the medical curriculum has been radically updated with a strong emphasis on patient safety, ethics, communication skills, the so-called 'humanitarian' side of medicine, I was able to relate a lot of what was being said to what I have learnt this year, and I strongly believe that this book should be incorporated into the curriculum as a way to highlight the topics we are being taught.

In summary, *The Other Side* touches on a number of issues such as attitudes to death, DNARs and palliative care that healthcare professionals will find interesting. Whilst Kate confidently offers her opinion on these topics, they are not the main focus of the book.

The main focus of the book, and in my opinion the reason why you should read it is that by experiencing the hospital setting as a patient rather than a professional, Kate has a unique and valuable insight that she has been able to use to make a number of simple but significant changes to her practice that allow her to better relate to and communicate with her patients.

It is fortunate that the majority of us will never be put into this position, though by reading her book we can still benefit from this unique insight and become better clinicians.

James Gupta

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Review of *The Other Side* by Jennifer Klimiuk, SpR Palliative Medicine

'The Other Side' by Kate Granger is a surprising and incredibly insightful piece of work. It is a graphic and truthful account of the author's personal experience as a patient with a terminal disease. The author, a Specialist Registrar in Elderly Medicine, was diagnosed with a rare type of malignancy at only 29 and this book offers her unique, intimate and emotional insight of this experience through the eyes of a doctor.

The author writes articulately and candidly about her journey from diagnosis, to treatment and beyond. She describes the often unpleasant daily experiences of life as a patient which, as doctors, we often dismiss as routine; what this book illustrates is they often have profound and distressing impacts on patients and their experience at the hands of medical professionals.

One could argue after reading this book that it is worse to be a patient as a doctor, owing to the 'burden of knowledge'. The opposite can also be argued, at least we as doctors have understanding of the basic processes behind what happens- simple questions like 'why am I seeing a different doctor every day?', 'what happens next?', 'what is this next scan for?' are easy to discern for clinicians but others do not have that same insight. What was also evident from this story is how utterly gruelling, unyielding and bewildering cancer treatment can become for some patients and what relief can often come, physically and emotionally, from focusing on palliation and moving towards this ultimate purpose.

This account highlights to a startling degree how communication skills amongst professionals can vary and what an impact this ultimately has on the emotional and psychological state of a patient. A small, indifferent gesture can have a huge impression upon a patient in a vulnerable state and clinicians are often blissfully unaware of the inner turmoil patients are suffering. It is evident, especially

from this book, that if communication were better, the overall experience of patients would ultimately be better. Communication does not eradicate pain, nor does it change the need for surgery or remove the upset of a terminal diagnosis. It does however eliminate the anxiety and uncertainty associated with many of these, anxiety that is driven by a multitude of factors, not least a lack of understanding or a simple feeling of facing things alone. Many medical professionals feel uncomfortable that they cannot 'change' what is happening for patients and this causes distress for them. Ultimately, patients don't expect that from us, they want someone who will be honest and clear about what is happening, someone who will discuss the uncertainties with them, someone who will listen to their concerns even if they can't change them – someone just human.

Communication skills are a much greater focus in Medical Undergraduate and Postgraduate teaching today but there are still many misconceptions about how to approach patients, especially those with a terminal diagnosis. This book should be an absolute must read for every medical student and doctor. It highlights the small things that we take for granted that can be a source of immense anxiety for our patients when they don't understand what is happening and it shows that good communication doesn't always have to be an hour long conversation about prognosis and expectations, it can simply be a reassuring smile, a short explanation or a bit of honesty when things are uncertain.

I hope this book gives confidence to those who read it and they see that it is in the small day to day things where we can often have the greatest impact for patients. Ultimately, we need to see that we are not Doctors administering to patients or professionals looking after the public; we are human beings caring for other human beings, it is never wrong to remember this.

Dr Jennifer Klimiuk

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Review of *The Other Side* by Anne Arber, Senior Lecturer in Cancer and Palliative Care

Kate Granger, a highly experienced doctor (Elderly Care Registrar) suddenly becomes seriously ill with an advanced cancer while holidaying in California. She was in the midst of a fantastic family holiday when she had to be taken to the Urgent Care Centre and her journey to becoming a patient with advanced cancer starts. *'The Other Side'* is her story of being a patient through a doctor's eyes. She hopes that health care professionals will read her story and get an understanding of 'what being a patient is really like'. Once I started reading the book it was hard to put it down; it is so vivid, sometimes funny but also disturbing. What stands out to me are all the examples of poor communication from the health care professionals, regarding breaking significant news, managing the treatment pathway, preparation for and reporting the results of invasive tests. Kate works hard to keep her dignity, through invasive investigations and intimate physical examinations.

Kate returns to the UK health care system where she finds her GP practice has a good system with a named GP allocated to her. She is admitted quickly to the hospital admissions unit and this is where it becomes frightening for her. She picks

up from the white board on the ward that she is to have an MRI scan – nobody has discussed this with her. She can hear every word of the nurse's handover, including the reference to her as bed 27. Things do not get any better, a registrar whom she has not met before breezes into her room without knocking and asks Kate why she is upset. When Kate replies that she is 29 and has cancer the registrar's reply is: 'you are too young, it will be something benign'. This is just so crass Kate asks her to leave. Later on, a gynaecology Senior House Officer whom she has never met, enters the room looking nervous, sits down and out of the blue announces 'your MRI shows evidence of spread'. She is astounded by the lack of skill in delivering bad news, there is no warning shot. He goes on with some false reassurance: 'they think it's a germ cell tumour, which should be very treatable'. In fact this turns out to be far from the situation Kate finds herself in. In the future I can use these examples when teaching how not to break bad news. The problematic communication continues with the clinical nurse specialist using lay type language to explain chemotherapy, which Kate finds patronising. Sadly many of the staff's communication skills do not live up to Kate's expectations and I found this distressing. When she is moved to the specialist cancer centre the quality of the medical and nursing care including communication is significantly improved.

The oncology nurses are 'brilliant at multi-tasking' know how to manage her pain, have excellent aseptic technique and the consultant is described as 'a lovely oncologist', he has a gentle manner, listens well and shows great empathy.

This is a great book, which is a really helpful resource for teaching medical, nursing and allied health professionals. This book should be required reading for all medical and nursing students. Kate's story raises many questions about dignity in care. The Royal College of Nursing has put 'dignity at the heart of everything we do' and the General Medical Council is using patient and colleague feedback for capturing evidence about whether doctors are delivering dignified care. We need to do more; some staff are seriously out of their depth without the tools, strategies and skills to deliver dignified care especially in the area of communication and information giving. More 'on the job' training with junior medical staff regarding breaking significant news and information giving such as Advanced Communication Skills training is a priority for this group.

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Questions-&-Answers with Dr Kate Granger



You started to feel unwell last summer while on holiday in California; briefly tell us about your cancer diagnosis and treatment experience from that point...

A few days into our trip I began to feel unwell with some back pain and nausea. My symptoms rapidly worsened necessitating admission to an American hospital where I was diagnosed with acute renal failure caused by both my ureters being obstructed by multiple soft tissue masses within my abdomen and pelvis. They patched me up in the US and we came home to pursue further investigations and treatment in the UK. The diagnostic process was not straightforward and I needed several biopsies and scans to work out that I had a Desmoplastic Small Round Cell Tumour (DSRCT) which is a very rare and aggressive type of sarcoma. The cancer had metastasised to my liver and bones. Unfortunately whilst the diagnosis was being made I became very unwell again with renal failure and sepsis, which necessitated me undergoing multiple painful invasive procedures. Eventually I was well enough to undergo chemotherapy, which was really the only therapeutic option for me. The chemo was given every three weeks as an in-patient for four to five days, with a few days break at home before being readmitted after every cycle with febrile neutropaenia. After five cycles on New Year's Eve I made the difficult decision to stop chemotherapy

and get on with living my life. I am very lucky to have a chemo-sensitive tumour, but the burdens of treatment had definitely begun to outweigh the benefits at which point I always said I would withdraw from treatment, knowing full well from the outset of my illness that the Oncologists were never going to cure my cancer.

How do you think being a doctor has affected your experience as a patient?

I think being a doctor patient has its advantages but also has its downsides. In some respects it makes life easier. I understand what is going on, I know what questions to ask, I feel confident to advocate for myself and question my doctors about their management plans to make sure any actions are best for me and to ask for things that I think would help me. Having contacts within the profession for advice is also useful; I have some good colleagues in Haematology and Interventional Radiology who have definitely influenced my decision making along the way. Sometimes though I wish I did not have as much knowledge and experience, for example knowing what is in store for you with regards to a procedure is not necessarily a good thing. Coming into contact with people I knew through my professional life when I was a patient was also very uncomfortable for me.

In *The Other Side*, although you recount that you received some excellent patient care, you also note that you experienced episodes of poor doctor-patient communication; tell us about the features of these episodes and how they made you feel as a patient...

It is easy to criticise poor communication but I do recognise how difficult it can be to have these conversations. I think remembering the simple things when communicating with patients is so important. For example I was told I had metastatic disease without any clarification of what I already understood, with no warning shot, with no opportunity to have anybody with me and the nurses were not told that I had just received such devastating news. The doctor could not leave the room quickly enough after

delivering this news and I never saw him again. Receiving news like that is never going to be a nice experience but I'm sure it would have been easier to hear if I had been supported by my husband and the conventional communication structure had been adhered to. I think it is also important to think about the environment and setting when communicating with patients.

I remember being seen on a ward round once with eight people staring at me. I felt like a circus act and there was absolutely no need for all those people to be present.

From your perspectives as both doctor and patient, why do you think it is that doctors sometimes get it wrong when it comes to patient communication?

I think we as doctors are all incredibly pressurised in our jobs and sometimes 'breaking bad news' can just be seen as another task in a busy day. It is all too easy to forget that for the individual patient that this is their one and only opportunity to receive this news and doing it badly can cause immense and irreparable psychological harm. I think some doctors are extremely good at relating to their patients and showing true empathy, but that some others struggle with this and much of it is simply down to personality. On occasion I think doctors forget that being a patient can be very frightening and even something that seems simple and straightforward to us such as an MRI scan can be hugely scary to a patient.

You have returned to work three days a week; do you think your experiences as a cancer patient have altered your own clinical practice?

Definitely. I am much more patient-centred and empathic now. I understand how scary it is to be sat in a hospital bed so I try to take more time to explain investigations, procedures and treatments properly to my patients and allow them time to discuss their questions and concerns. I also have a better understanding of the vulnerability, indignity and embarrassment of being a patient these days and remember this especially when I am examining patients. I am probably a stronger advocate now and will push harder for what I believe is right for the people I look after than »



I did before my own illness. One of my main focuses at work is providing good quality Palliative Care in the acute hospital setting and I invest a lot more time and emotional energy into looking after my patients in the final days of their lives and making sure their families are well informed during this difficult time.

What messages from *The Other Side* do you hope that doctors and health care professionals will take away and implement?

One of the aims of the book is that healthcare professionals will recognise the importance of the 'little things' such as holding a patient's hand when they are upset, sitting down next to them on the same physical level rather than standing over them and recognising the impact of illness on the individual rather than thinking of patients just as their disease entities. These behaviours are small and easy to achieve but have a huge impact on making patients feel at ease with the people looking after them and their ability to relate to and trust these people. I was very lucky to be able to advocate for myself effectively throughout my illness but I hope the book emphasises the need to be doctor to but also advocate for your patients. I also hope that by reading the book doctors may take just a little more time to properly listen to and respond to their patients' needs. ■

After *The Other Side*, *The Bright Side*...

Next month, Kate will launch a long awaited sequel to *The Other Side*, titled *The Bright Side*, in which she writes about getting back to work and how her experiences as a patient have changed her practice as a doctor. *The Bright Side* also looks at living with a terminal diagnosis and the struggle to maintain positivity.

Excerpts from the forthcoming *The Bright Side*...

I'm not sure what the etiquette is for living life with a terminal cancer diagnosis hanging over you. I guess there is no rule book for a situation like this and I am very much of the opinion that I can only do my very best to plough on with things and try to be as normal and active as possible for as long as possible, bearing in mind that I might feel rubbish and that things may start to get on top of me both physically and psychologically at times. I am therefore packing as many activities into my life as is humanly possible. I have quite high expectations of what I can achieve in my remaining time; some might feel these expectations are set too high. I have always been an ambitious individual though and this aspect of my character is not going to change just because I am dying.

Why as a cancer patient are you seen as 'heroic' and a 'fighter' if you accept all the burdensome, in the most part futile treatment for incurable cancer? Does this mean that if you refuse these interventions that you are somehow foolish or weak? I have been thinking about this a great deal recently. There is a tendency for media surrounding cancer to use highly emotive language. For example the Cancer Research charity slogan is 'together we will beat cancer'. No we won't. It is a result of being a living organism that cell division and repair will sometimes go awry and the result of this will be cancer.



We may become increasingly capable of counteracting the pathology, but I cannot imagine there will ever be a human society without cancer. I do not mean to say that people who choose to go through lots of treatment are doing anything wrong if this is truly what they want to do, but I think all too often patients feel under external pressures to battle on when deep down inside they just want to enjoy their remaining time without so many medical interventions. Death and dying are such taboo subjects in our Westernised society and I have never understood why, after all it is the one thing that we all have in common, we are all going to die one day. There are campaigns and organisations out there such as 'Dying Matters' tackling these issues but it is going to take such a monumental effort to change societal attitudes. Acceptance is a hugely difficult thing.

All profits from the sale of *The Other Side* are being donated to the Yorkshire Cancer Centre which is the fundraising arm of St James's Institute of Oncology, where Kate is being treated. To buy a copy of Kate's book (£10), please visit www.theothersidestory.co.uk