

October 2017 Written by Jennifer Short

REFLECTIONS

I am a core medical trainee who has wanted to pursue a career in palliative medicine since medical school. I have found many opportunities to gain valuable experience in the specialty, but recently I have very sadly gained a greater insight than I would have wished: my best friend passed away. She was diagnosed with a rare, aggressive cancer 18 months earlier and underwent several treatments and procedures, but unfortunately none were able to get rid of the disease. It is cruel and unfair (probably a daft thing to say: it often is I guess). She was a doctor too. Throughout this devastating time, we have seen healthcare through different eyes, from the inside, and I have noticed things, good and bad, often just the little things, but things that make a big difference, and I thought it would be good to reflect and to share, to learn lessons that might make a small difference to us, our patients and their loved ones.

Doctor as patient

Firstly, some thoughts regarding looking after a patient who happens to be a doctor.

Don't be intimidated when treating patients who are doctors. We are all 'normal' people and in that situation, many of us will feel vulnerable, scared and out of control. We may just want to be treated like everyone else, to have things explained simply and thoroughly, and for no knowledge to be assumed. We will still want to be cared for and guided, and for someone else to be our 'responsible clinician' – that should not have to fall to the patient, they have enough to deal with. This of course will be different for each individual – as it is for every other patient. The rules still stand: treat each patient as an individual, be guided by them.

When breaking bad news to a patient who happens to be a doctor (or to a relative who is a doctor) good communication skills may become even more important. That person should, as much as possible, be protected from having to relay that information. It is not fair, nor appropriate, so make sure you take time to ensure that loved ones also understand. This may mean multiple conversations aimed at different levels but it is invaluable.

In addition to this, always bear in mind that what you are *not* saying is also important. Often we use 'signposts' when breaking bad news, give vague, brief information until we have a more definitive diagnosis and plan. However, this can be difficult with those who have some knowledge. They may be told that 'the bloods and ultrasound show that the kidneys are bigger than they should be and are not working as well as they should be and this needs further investigation.' A patient with medical knowledge may read into this what was *not* said, 'it is very likely that the cancer has spread'. If not handled appropriately, this then puts them in a terrible position – do they break this potential bad news to their relatives, or do they quietly go along with it, silently distraught?



Doctor as loved one

Going from the role as doctor to the role as a 'loved one' if one of your friends or family is unwell is hard. Really hard.

The job we do is often tough at the best of times, but when you are dealing with a patient with a similar condition to that of your loved one, or when you are breaking bad news very similar to the news that has just been broken to your loved one, it can be unbearable. I have found that there is a 'put on a brave face and get on with it' attitude within our profession. This is not helpful, to us or our patients. We need to find a way to look after ourselves: peer support, senior support, friends and family, and time off work if necessary. You need to be able to be focussed on your job and your patients when you are there, so if that means taking some time out to focus on you and your loved ones then so be it. You need to be safe.

As I've already said, knowledge is hard. Equipping yourself with knowledge by researching the condition, treatment and prognosis can be beneficial and may help you to cope and also allow you to guide your loved one. However, it can also be dangerous. Firstly, you may not know the full details of your loved one's case, so any research you do is unlikely to be specific to them. Secondly, you are putting yourself in a difficult situation if you know more than your loved one. If they chose to not know about their prognosis, for example, it is unlikely to be a good thing for you to know. Your job now is to support them, in the way they want to be supported. Don't try and be their doctor, they will have enough of those.

The insight gained as a loved one in this situation can also have some positives and you may find new ways to help your patients: point them in the direction of a support group you may have heard your friend talk about; anticipate some of the issues they may face; understand just a little bit more how they, and their loved ones, might be feeling. But always remember that every person is different and never assume that just because you and your loved one coped in a certain way and wanted a certain amount of information, your patient and their loved ones will be the same. Keep a distance and keep perspective. The support and understanding of colleagues will play a big part in this.

Doctor of a patient at end of life

As I said at the beginning, I have wanted to work in palliative medicine for a long time. Throughout this journey with my friend I have at times questioned this desire and whether I have the strength to cope in such an emotional specialty. But these doubts have only ever been brief and ultimately I have been inspired by the palliative teams I have seen care for my friend. Seeing the palliative specialist teams from this point of view has also highlighted some important points to me which I think we can all learn from as doctors looking after patients at the end of life, whether in the palliative specialty or otherwise.

My experience as an 'insider' has made me realise just how difficult good, effective communication is, especially with end of life issues. Palliative consultants discussed difficult issues with us and they were amazing, explaining things clearly to us all and giving opportunity for us to ask questions. I would view these consultations as 'successful' and ones for me personally, to learn from. However, when non-medical loved ones later asked me certain questions, I realised that what you think people have understood from a conversation may be very different to what they actually have, especially when the topics being discussed are conceptually hard, as well as being emotional. As much as you can, go back, discuss again, ask them



questions, as well as answering theirs. This may just help clear any simple misunderstandings, which may make a big difference.

You can have a big impact, not only for a patient but for those around them. How loved ones experience that death will make a huge difference to how they feel about and approach deaths they will have to face in the future, including their own. Simple things like staff using our names and showing genuine care by listening to our concerns and thoughts and making suggestions as to how we could care for her and spend those final days with her, guiding us through that part of the journey, made us all feel supported and cared about and empowered us to be there in the best way we could be at such a sad time. The memory of that compassion will stay with me for such a long time to come. As I said, much of this is simple and comes with just having basic empathy. But it also easy for it to get caught up and lost when you're dealing with the day to day struggles of being swamped by the never ending tasks that need to be completed at work and the constant plate spinning that is involved in trying to maintain a healthy work life balance. We all know how hard it is and that frequently plates are dropped, but the next day we can pick them up and start frantically spinning again! But for that patient and their loved ones in that moment, this is the only thing that matters and there isn't another chance to get it right. They need the support now. They need to be able to ask those questions now and not to feel rushed. Of course this is hard if you have to leave to do the school run and I don't have any magic answer as to how to achieve this balance. I guess it is just about having these things in mind, trying to keep perspective and doing the best we can do at that particular time. Hospice staff seem to be amazing at this and I would encourage hospital healthcare professionals to spend more time at hospices, which are specifically set out for this purpose and where there is, in general, more expertise and time to focus on these aspects of care, and take back with them the skills learnt and experiences gained to the busy, less than ideal, hospital environment.

Practical points

Lastly, I would like to highlight a few general, practical points. These are things which seem like common sense and I'm sure we would all like to think that we do them, but I see on a day to day basis people not doing them, myself included.

Ask the patient. Remember that patients will often know a lot more about their condition and medications than many of those around them, including healthcare professionals, especially in complex cases. Listen to them and ask them questions, where appropriate of course. You may need to confirm things with healthcare professionals, but it can be much more time effective and accurate to walk to a patient's room to check the drugs they are on for example, than trying to get hold of GPs, pharmacists, specialist nurses etc. It is also respectful to acknowledge that they have been competently managing their condition prior to coming into hospital.



Keep patients informed.

It is all too easy for us to take on the role of the person in charge of the patient's condition and by doing so remove their control and involvement when they are hospitalised. Put yourself in their shoes. They lie in bed all day and have things done to them, and often we don't even inform them why or the results. The big procedures we are of course much better at, but how many times do you explain to a patient why a phlebotomist will be coming round to take blood from them in the morning, and later that afternoon when we sit and look at the blood results on a computer, how often do we go and inform the patients of the results, even when they are normal? Often it would only take a few extra minutes, but it is very important to the patient.

Complete death certificates as soon as you can. I completely understand that it is often one of a very long list of jobs to do and that we often have too many sick patients to look after, but I feel it is often not given enough of a priority by junior doctors. For that patient's family, getting the death certificate means that they can get on with making arrangements, and having to wait even one more day for it, can make a devastating time even more distressing.

Conclusion

This is of course, just my reflection and my opinion, not based on any research in any way, but my thoughts on my experience. It focusses on issues that occur when the patient and/or relative is a doctor, but the points are relevant to all patients and our day to day work in general. I hope that it gives a slightly different perspective on some issues, that we can all learn from and reflect on in our roles, whatever they may be.