

## What matters the most now when life is like a Shakespeare play?

### The playbill

The famous playwright has no need of introduction, certainly not to any of you. It is I who might need one.

I spent the last nine years working as an anaesthesiologist and intensive care physician at the First faculty of Medicine, General University Hospital in Prague. In the last two years, I gradually shifted half my focus towards both inpatient and outpatient palliative care, and I am currently working on both a palliative care specialty certificate and my PhD at the Palliative Care Clinic at the same hospital. I have a wife some of you met last year, who is an internal medicine specialist, and a beautiful son who is a diaper and duckie specialist.

Before I start with the talk, I should ask you all to take any statements or observations I might make here with just a grain of salt. I am not an official representative of any of those institutions, I am here bearing just my personal experience. I am aware that many of you may also have deeper knowledge than anything I may come up with. I am still a student of the medical trade; my experiences are generally far beneath yours and I came to learn from you. Finally, I feel like I still understand Shakespeare too poorly for such an audacious title, so bear with me please. But I will try my best.

### I. ACT 1: An ethical force-field.

*"Let me be that I am and seek not to alter me." (Much Ado About Nothing, Act 1, Scene 3)*

Let me begin with a broader outline. Young graduate physicians in my country are the first physician generation that has not been moulded by a totalitarian system; a system that wanted to decide everything for its subjects. We grew up in a society that rediscovered personal freedom and individual choice, believing that an individual knows better for themselves. But healthcare has been somehow reluctant to change accordingly. As early as 2001, the Czech Republic has been a signatory to the *Convention for the Protection of Human Rights and Dignity of Human Being with regard to the Application of Biology and Medicine*. Since 2011, Czech patients are by national law not "patients", but clients of a healthcare service system. Their rights are being enhanced every year, along with a slowly growing number of malpractice lawsuits which were very rare in the past. The tide has turned, but it took more than three decades since the Velvet revolution for these ideas of ultimate personal autonomy to become really engrained.

I can only speculate why it has taken so long. Was it conservatism in our profession, anxious about changing protocols and habits? Was it cultural conditioning and the fact that both sides got something from authoritarianism – physicians got power, and patients got relieved of responsibility for their choices which – honestly – can be quite daunting? Is it an issue of resources, when a single oncology consultation in the

Czech Republic is valued by public insurance as lasting 10-15 minutes? When we still finance our system with 1/3 of EU and 1/5 of US expenditures, there is little resource available to talk to the patient as a Person besides the technicalities. The gravity of this issue is impossible to overstate. So, was it insufficient resources?

In the Czech Republic, the medical profession has repeatedly scored the highest respectability and trust ranking in surveys. Maybe we wanted to keep that respect, and we were anxious that we might lose it. Or maybe we were too anxious about our failures? Is it because we are the most atheistic nation in Europe? Maybe we lost eternal reassurance and lost the courage to look the death and the misery of illness in the eyes – and that is why we began to rely on ‘victorious’ Evidence-based medicine (EBM) even more strongly. Is it a coincidence that palliative care providers tend to be the few among healthcare professionals who have a spiritual background?

Or maybe it is misplaced compassion. Healthcare attracts compassionate people. But compassion can drown people in itself. It hurts when it is blind, when it stops seeing the other human as a person and forces them to accept help they do not want and/or need. Like a Freudian devouring mother. After all, the force behind Communism is (I believe) misplaced, unbridled, uncontrolled compassion turned into tyranny.

And perhaps I am just too harsh. In HBO’s 2001 adaptation of ‘Wit’, a play by Margaret Edson, the fabulous Emma Thompson played a university professor expert in 17<sup>th</sup> century poetry, facing both stage IV ovarian cancer and a (purely Western) healthcare system lacking functioning palliative care. Her character suffers through dehumanization, insufficient autonomy, ruthlessness and many of the other flaws that plague us, and more. I highly recommend watching the play.

I will try to expand on my analysis as we progress further. I hope it will inspire you to do your own.

In the decades since the communist regime crumbled, Czech physicians and the general public started seeking answers to questions which they had not truly asked for so long: What is ‘good’? Are we doing good? Are we the ones to define what is good? If not – who should, if everyone is to decide for themselves and in the end, the final bill – financial, symptomatic, emotional – is being paid for the most part by the patient themselves? What do our patients truly want? What do they even know about their condition? How can we better inform them? What are their preferences and how can we help patients discover them?

I believe these questions are very close to the very point of Medicine of the Person. These questions are the beating heart of the transformation of the Czech healthcare paradigm I spoke about. Hospital palliative care wants to explore them all. Palliative care as a whole brings something that has been missing for decades – a deep appreciation of the fact that ultimately all efforts fail, and leaves inevitably fall in the autumn. Perhaps it is this realization that sharpens sensitivity to meaning and personality even in the most stubbornly paternalistic physician.

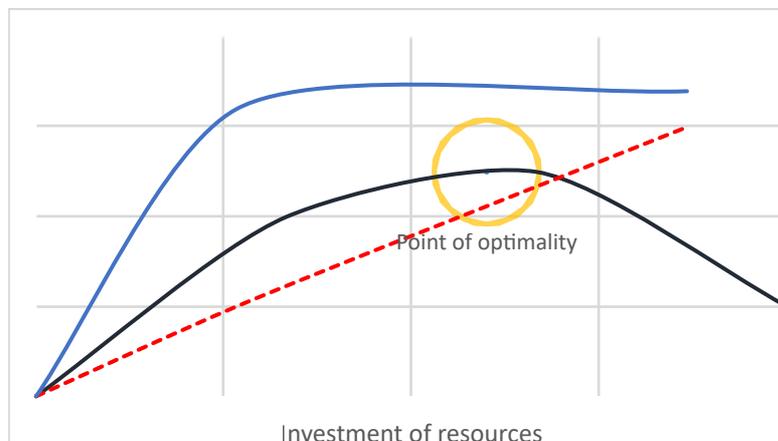
## II. ACT 2: We are no gods.

*"The fault, dear Brutus, is not in our stars, but in ourselves, that we are underlings."  
(Julius Caesar, Act I, Scene III)*

In 1985, Beauchamp and Childress postulated four main ethical principles in medicine. They defined them as Beneficence, Non-maleficence, Autonomy and (Distributive) Justice.



Paternalistic medicine had beneficence as the only ruling principle, making the Physician into God himself. The trouble with assuming the role of God is that you must deliver as God. The patient looks up to the physician to perform the magic rituals of science and surgery and give back health. Woe betide if the physician cannot do that. That is when they either admit failure, increase the harm with invasive treatment, or the patient has to be abandoned altogether.



The paternalistic approach is thus revealed as dysfunctional through insufficient patient autonomy.

All principles in the force field need to be in balance. I dare say there can be such a thing as too much autonomy – that we are truly just spectators of a drama, untouched, indifferent. That we remove ourselves from the struggle and coldly offer too little guidance. I dare say there can be too much distributive justice, when we distribute resources too randomly, skipping painful decisions in scarce resource settings posed by events like the COVID pandemic. And I dare say there can be too much non-maleficence, so much that we are scared to do anything and become alibistic (acting defensively to produce an alibi for our actions).

Mere intent to do good is insufficient. We need to seek wisdom.

#### **i. Length of survival is an insufficient guide for practising Medicine of the Person.**

As students of medicine in Czech Republic, we were trained to use our evidence-based medicine (EBM), our Kaplan-Meier charts as a measure of success. As doctors, we were trained to keep the patient alive. That was what shaped our decisions. We thus administered fifth line chemotherapy to a dying person because it meant the patient would live three weeks longer. In ICU, we used all the gadgets we could – invasive ventilation, dialysis, invasive monitoring, reserve antibiotics. We sent the patients to their fifteenth surgery, we gave them chest drainage, we put all kinds of catheters inside every orifice – and more. We fought for longer duration of their stay on Earth.

It is striking that Overall Survival (OS) is one of the most convenient variables to measure and acquire. A simple request at the state registry, and you got your data. It is a very definite, very convincing parameter. It is clean and easy to present at medical conventions. It is *almost* bias-free.

All the effort we put in, happens at tremendous costs to the patients, to us as physicians and to the system. Is it worth it? Is it meaningful? Is it so for all patients?

Don't get me wrong please. I am not saying EBM is a bad principle or that overall survival charts are useless or that intensive care medicine should be abandoned. But individuality, values, principles of the person living in the hospital bed often go unnoticed. Maybe because they are far harder to measure. To be sure, some patients do want us to prolong their life as much as possible. But most – if asked properly – will say they have a range of values. Some of those values may be more important to them than mere survival. Everyone has a different concept of a life worth living.

## ii. Appropriate care.

The concept of Appropriate care addresses many of these issues.

<i>Appropriateness of care</i>		<i>Medical indication</i>	
		<i>YES</i>	<i>NO</i>
<i>Patient preference</i>	<i>YES</i>	<i>YES</i>	<i>NO</i>
	<i>NO</i>	<i>NO</i>	<i>NO</i>

Table 1: Appropriate Care (courtesy: Prof. Michalsen, Germany)

On the top right is “Medical indication” – the realm of EBM and professional opinions of what should be done. Bottom left addresses patient preferences, their will, their values based on their understanding. In this concept, only interventions in the green area – that are both medically sound *and* preferred by the patient - should be done. When uncertain, a therapeutic trial period for clarification can be offered.

An intervention that is medically sound, even if strongly recommended by guidelines, provider experience and EBM data, but one not agreed upon by the patient (e.g. a patient refusing therapy for curable cancer), should *not* be followed through. The role of the attending physician here is to reach a basic understanding as to *why* the patient is refusing treatment and to filter out confusion, anxiety and misunderstandings. In case there is reasonable doubt about the patient’s psychological health, psychotherapy may be suggested, or a specialist consulted. But a sovereign decision to refuse therapy that a professional views as warranted *is* within the patient’s right – it is *their* body and *their* values.

Therapy that is medically unsound but requested by the patient should also be avoided. It is necessary to have strong evidence to support our refusal, but no patient has the right to enforce his view on us. After clearing out all misunderstandings and filtering out emotional distress, a request to get medically unsound care should be politely declined. If another facility provides such care and is willing to provide it to the patient, cooperation with handover and transport should be offered instead. One exception to that rule in many countries including mine is a request to administer lethal medication. Czech law does not allow for euthanasia, and even assistance or provider recommendation constitutes breaking the law. Therefore, by law, we cannot assist with that specifically.

And lastly – therapy that is both unsound and not preferred is best described as ‘medical hell’. Some may ask whether that even occurs. Imagine an octogenarian with a plethora of comorbidities, bedridden, who comes to the hospital with an acute abdominal issue. CT scan reveals bowel ischemia. The attending surgeon is highly doubtful surgery can help this patient, yet such diagnosis mandates surgery per surgical guidelines. The patient’s preferences are not explored due to time constraints and insufficient communication (family members could be asked for patient preferences if the patient cannot not speak for themselves). The result? Surgery is performed, causing unnecessary suffering and death in the ICU for the patient and ethical distress for the attending team.

## III. ACT 3: Select cases

Listeners should be advised that cases I will talk about do not represent the overall picture of everything that happens in our hospital. They rather reflect my personal experience.

Act three in a classical Elizabethan drama is reserved for the Climax. The conflict reaches a turning point. The consequences of the hero’s actions begin to become apparent, and the hero realises his error. Shakespeare’s dramas tread at the frontiers of our hearts and minds. His characters face dilemmas that often put us on the edge of our seats. However, it would be very different to not merely spectate, but to find oneself up on the stage – in a hospital bed, facing crushing dilemmas personally.

In palliative care, sometimes it is as if the master playwright wrote what unfolds before our very eyes and ears. And sometimes it is not even Shakespeare but Samuel Beckett.

So, hear ye.

*"Give sorrow words; the grief that does not speak knits up o-er wrought heart and bids it break." (Macbeth, Act 4)*

One day I was to deliver serious news to a patient at the pulmonary clinic. The news was *not* that his Stage IV lung cancer was incurable and that he had months to live. I listened to him and asked how much he knew about his health and asked about his family. He told me how the only joys in his life were his only son and grandson, that they lived with him and all he desired was to go back home. He named his son as his Person of Trust. I asked him how life in the hospital bed was and whether we could do something to make it easier. I offered changes to his medication (to help him feel better). Finally, I asked him how he wished to hear potentially serious news. He wanted to hear all of it.

The news I was bringing this man was that his son had hanged himself and that his family did not want to come and visit him. In fact, they did everything they could to prevent him from going back home. I later understood that he somehow hurt his step-daughter, but never learned how exactly. I could not give him what he wanted, although I said I would very much like to. He did not believe me that they did not want to even speak to him. Ultimately, his step-daughter mustered courage and agreed to have a short talk with him over the phone. Only then was the veil removed. We became his only companions for a short while, until he was transferred to a nursing home, away from our hospital. As far as I was able to follow him up, he died alone months later.

*"My tongue will tell the anger of my heart, or else my heart concealing it will break."  
(The Taming of the Shrew, Act 4, Scene 3)*

I was called to see a man in his eighties, who was the sole carer for his bedridden wife. He had started turning yellow lately and got progressively more tired. His doctors found a large mass in his abdomen, just below the liver. They told him they could not do much else other than put a stent in his biliary duct. When we came there, he told us he was a former soldier. He was visibly nervous engaging with palliative care and eventually asked us to leave. We said we were OK with it. He refused any other talks with us. I believe it was so he could kick death out of the door with us and my role was to give him the autonomy to do so. The attending doctor made the necessary arrangements with his daughter instead. He died shortly after.

*"Such as we are made of, such we be."  
(Twelfth Night, Act 2, Scene 2)*

I had been called to a man with bladder malignancy and repeated bleeding. The issue was that he kept on refusing treatment at the last possible second. They would explain it, he would sign the consent form, they would transfer him to the operating room, prep him, and then he would change his mind. This happened at least four times. To say the attending team was frustrated by it is a gross understatement. I found him bedridden, the disease having taken most of his strength. He said his strongest desire was to be of use to other people. He spoke about children he had not met in decades. And then he told me he was a criminal who hurt people and spent time in prison. He felt intensely guilty about his past. He said he also wanted to die. He could bleed to death any time.

We uncovered part of his guilt. I spoke about powerlessness – that I saw how hard it was for a man who shaped the fate of others to find himself so helpless. But then I said there is hope and that he is incredibly powerful right where he is. He was hanging on to every syllable. I said that with a simple phone call and an expression of regret, with a few honest words asking for forgiveness, he could change lives forever. For the first time in my career, I saw a spiritual emergency and I called for a chaplain to attend to this man. I don't know whether he made the call, but his bleeding stopped, and he lived on for quite some time.

I kept thinking about why he kept refusing the procedures at the last moment. Maybe it was because he was used to denial, hate and violence. Being met with help and compassion was too much for him and he

started punishing himself for what he had done by refusing help. Maybe there was something he had done that nobody else knew about. I did not learn any more.

*"If it be now, 'tis not to come: if it be not to come, it will be now: if it be not now, yet it will come: the readiness is all."*  
(*Hamlet, Act 5, Scene 2*)

I met a forty-two-year-old, sun-tanned father of three hockey-playing boys (aged 16, 14 and 12) who used to ride 80 km a day on a bike. He lost 30 kg of body muscle in a mere month since he first started feeling unwell. Doctors told him he had aggressive, anaplastic lung malignancy. He wanted to fight, having been a warrior all his life. He wanted to be there for his sons. He could not, and while he was fighting a lost battle, we helped his wife cope and prepare for the inevitable. We talked with him, explained alternatives while we helped her understand, set up economic failsafes and helped her talk to the children. He finally fully understood that he was dying when he was at home, in hospice care. Three days later, he died, a heart-wrenching two months after his first symptoms appeared. I do not know if we met his expectations, but we did what we could.

*"Love alters not with his brief hours and weeks but bears it out even to the edge of doom."*  
(*Sonnet 116*)

I went to see a man diagnosed with amyotrophic lateral sclerosis in his fifties. His wife was there, I brought our social worker. The patient had to decide whether he wanted to live a dependent life, being subject to passive hygiene in total powerlessness, being breathed into by a ventilator and fed by a tube. We offered alternatives as to what we could do. His wife was in tears, but told him in front of our eyes, how she would love him until his death and whatever happened, she was willing to help, should he decide to be here longer. Then she said she loved him and if he did not want to bear this anymore, she was not holding him back, and he could go. We felt we were treading on holy ground as we sat there.

*"Oft expectation fails, and most oft there where most it promises; and oft it hits where hope is coldest, and despair most fits."*  
(*All's Well That Ends Well, Act 2, Scene 1*)

A year ago, I began consultations with a genius IT consultant with a (measured) IQ of 164. I met him shortly after his physicians told him he had malignant mesothelioma in his pleura, abdomen and pericardium. In the past, he was also a member of a team that filed the national drug agency application for Keytruda, by coincidence one of the possible treatment options for his illness. By the time of his first Oncology consultation, he was better versed in available scientific literature than both his oncologist and me. He scoured every corner of the Internet. He wanted hope, not white lies.

He also had two children with two different women and was living with a third. Later while we took care of him, we found that his first partner was dying at the same time with acute liver failure. We took care of her too. He died on January 13<sup>th</sup> this year. His third partner, who literally carried him through, is currently getting IVF sessions to have his baby.

*To be, or not to be, that is the question: / Whether 'tis nobler in the mind to suffer / The slings and arrows of outrageous fortune / Or to take Arms against a Sea of troubles / And by opposing end them: to die, to sleep.*  
(*Hamlet, Act 3, Scene 1*)

A lady came to our office after receiving a diagnosis of bulbar amyotrophic lateral sclerosis. She could use her arms and legs without any problem. But she could not swallow. Her social discomfort associated with managing her salivation was too much for her to bear. She tried everything available. She had a niece, diagnosed with a metabolic disorder, who was living with a tracheostomy and permanent care. That lady concluded she wanted to die and came to us to give her a date of her death. But she did not want to die at the moment. She did not understand what made her current life worth living even though she asked for removal of the problem.

I heard from my patients about loneliness and broken relationships, I was kicked out of the room, I sat in silence to countless tears, I had been a lightning rod for anger and frustration. I was asked for euthanasia. I helped formulate Advance directives. I coordinated assistance to those whom we could help a bit.

As an anaesthesiologist shortly after the start of my career, I met a man who survived his 22<sup>nd</sup> surgery for his acute pancreatitis. Anyone who has spent some time working at an ICU can tell how a patient looks after such an ordeal. Nobody asked him what he wanted. I realised I need to do things differently.

#### **IV. ACT 4: How can we do better?**

##### **i. Have utmost respect for patient integrity and personality.**

We are no technicians to a machine. We are fellow human beings. Let us never forget that.

##### **ii. Communication is a dance.**

Talking to all stakeholders in healthcare is essential, especially talking to the patient. However, it is often enormously complicated to just listen. In schools, we are being taught facts. A single difficult ICU case is worth literally hundreds upon hundreds of pages of lab results set in the centre of thousands of textbook pages and an ever-swelling amount of scientific evidence online.

As anaesthesiologists, we sometimes cannot listen because we are too full of those facts. And once asked, we happily deliver those facts. But most of our patients and their families do not need a list of lab results and a detailed explanation of Meropenem MIC (an antibiotic) for ESBL Klebsiella (a multi-resistant organism). They often ask whether they or their loved one will ever get better. Whether their illness is curable. They are looking for hope. They want to know what their life will look like in the future. For many of them, every physician's word is measured with their hopes and worries ten times more than with rational thought.

Communication about an illness in an emotional context is by an order of magnitude more difficult. It is like dancing in a minefield. It takes skill that has not been routinely taught in our country. And doing that in the time-constrained setting of an outpatient consult resembles a waltz in the minefield while being shot at. Skill is literally vital here.

##### **iii. Asking the right questions**

If we want to align our patient preferences with our offer, we need to learn to ask what those preferences are. And this time we really, really need to 'go gentle into that good night', even if we do 'rage against the dying of the light', quoting Dylan Thomas.

First and foremost, we need to ask *to what extent the patients prefer* to know what is going on. They should be the ones in control of the flow of information, not us. "How much would you like me to speak? Should I go in detail, should I present just the outlines, should I not talk about the results at all? Or should we talk with your loved ones about our next steps?"

We need to understand what they hope for, what are their worries. We need to assess their prognostic expectations. And we need to be gentle doing so – so that we always sympathise with their emotions. "I wish for the best for you, and that we could give you all you hope for".

And then we get to ask the greatest question of all: 'What is the most important now?' 'What matters the most to you?'

We need to hear the answer well. Maybe it is length of survival, maybe it is absence of pain, maybe it is being able to walk their daughter down the aisle or being there for the birth of their first grandchild, maybe it is going on that trip they delayed so long. Or just being home. Every individual has their own set of values, their own world. Based on what we have learnt, we need to reach a mutual understanding of what are the options and outcomes, to make the patient competent to reach a truly informed decision together.



- 2) U (understand what the patient knows/wants to know → learn where they are. Avoid yes-or-no type questions, pose open ones instead.
- 3) I → inform starting with a headline, *then give a pause to observe emotions*.
- 4) D (demonstrate empathy) → note emotions you see, normalize them, empathize. Avoid using statements like “I know how that feels like.”, instead, say “I see that you...”.
- 5) E – equip them for the next step. Only now add more rational information. Repeat attention to emotions (point 4) whenever necessary.

Physicians routinely disclose serious news in the hospital. Having the knowledge that the emotions are to come and how to deal with them is key.

## **V. ACT 5: Let us seek better understanding**

I am speaking as an anesthesiologist and a junior palliative care physician. I firmly believe that we cannot define what is good for our patients. Each individual deserves respect for his autonomy in the force-field of ethical values. Our decision-making should be shared with partnership in mind. We should seek our patient's true preferences and values. And do only those things that are aligned with them and medically sound.

Palliative care is somewhat special in these circumstances. We are enacting the change by defining and protecting basic ethical principles (with stress on patient's autonomy) while approaching the end of the patient's life. We desire to pay the utmost respect for our patient's personality and preferences – to truly live out ideas of Medicine of the Person – not Medicine of the Lab Result or Medicine of ‘Successful’ Surgery. In the beginning, we stood only at the end of life, taking care of patients who were to die in matter of hours, but now we do so much more. Respect transforms the whole medical system, liberates its inhabitants, doctors and patients alike.

### **i. Enhancing patient competence in a changing environment.**

The paradigm shift in our society is clearly heading towards greater autonomy of truly informed patient choice – and away from blank waivers or giving carte blanche. The transformation is ongoing and accelerating.

The first hospice in the Czech Republic was founded by Dr Marie Svatošová on December 1st, 1994, building on years of effort by people who saw Medicine of the Person as crucial. Not the least among them was the man thanks to whose invitation I speak here today, Dr Petr Fiala. Through bureaucratic struggle and philanthropy (the latter being equally invaluable), more institutions were founded, including home hospice care. In the end, it took more than three decades for the palliative care movement to gain enough traction to achieve tangible change on a national level. At this point, the listener should be advised that I am a bedside physician. I am reaping fruit that was planted and watered by people wiser and more courageous than myself.

In 2019, a Czech Ministry of Health Pilot Project defined a basis for hospital palliative care teams, and the first Palliative care clinic was founded on January 1st, 2021. I have the honour to work there. Since the academic year 2021/2022, we teach all students at our faculty the fundamentals of palliative care. We teach them that they need to formulate their professional opinion first. What could be gained, what could be lost? What will happen in each alternative therapeutic pathway? What is the clinical evidence for each option? Then we teach them to put all their ideas temporarily away and carefully and skillfully listen - explore the patient's values and preferences, employing adequate communication skills as described. Only once the patient's preferences are established and explored, they can begin to define what is the appropriate thing to do - offering each alternative.



*Figure 1 - Winslow Homer: Two Guides*

## **ii. Final chapter: A mountain guide.**

We are no God nor gods. I believe we should seek what is appropriate for the human being, the person, the client climbing Mt Condition. We are more akin to mountain guides. There are many things we do not control and there is a degree of unpredictability regarding illnesses akin to a weather forecast. We are experts in diagnosis and treatment options. Like our ropes, harnesses and carabiners, we have our training, knowledge and skills, our EBM data. We can help manage the twists and turns of the patient's journey. We can talk about their prognosis to a degree, based on our experience and evidence, but we cannot guarantee a specific result. We need to adjust our approach continually as the environment and available information change. And just like mountain guides, we can provide encouragement and support to our climbers, give advice on scaling medical decisions and try to alleviate fears and anxiety. Just like mountain guides, we need to respect our climber's decisions and preferences, and include them in the decision-making process. Even if they choose to do something we personally do not agree with, the only thing that should be done is making sure they understand their choice, being offered enough time and attention to process their emotions, their situation, and possible goals – like discussing the next climbing move. And finally, we say we are also responsible for our integrity. Once everything is cleared up, it is within our right to say "I do not agree. If you can find someone willing to provide the help you desire, I offer all my assistance with getting you to them". I feel like a mountain guide.

I am honoured to teach medical students that and it is an incredible honour to do this job.

Thank you.

*One short sleepe past, wee wake eternally,  
And death shall be no more, death, thou shalt die  
(John Donne, Holy Sonnet X, 1609)*

*"The robbed that smiles, steals something from the thief."  
(Othello, Act 1, Scene 3)*