Peter Mez (<u>00:00</u>):

Good morning everyone. And thank you for coming out on a Sunday morning for this session. My name is Peter Mez. I present the national interest on ABC radio national. I'm also a member of the advisory committee of the festival of ideas, and it's a great pleasure to be the MC for this event with [inaudible]. I'd like to acknowledge that we meet on the lands of the gown people, the traditional company country of the Ghana people, the Adelaide Plains, and I pay my respects to their elders past and present. I think you're in for a very interesting discussion lecture and discussion this morning, and I will invite your questions to run Janet. After she'd spoken. I first came across Ranjan his writing in the Melbourne age as an opinion piece. And I found it very interesting and it led me to her book, which I read and I have to confess that running.

Peter Mez (00:58):

And it doesn't want me to say this, but for the last two mornings, her book has had me crying into my muesli. And she didn't want me to say that because she thinks that might put people off buying her book or reading her book. But I was crying for the best possible reasons if you like, which is that I suppose the, the ability of people to the bit, what you see in, in what runs and writes about people, dealing with death, dealing with a cancer brings out the best often in, in people and their humanity and their ability to manage those things. So those are some of the issues we were really dealing with some pretty essential issues tonight. So this morning issues that confront us in a very essential way as human beings, illness, dying and death. And I think it's really rare to find a doctor who writes so candidly and so carefully about their work. I mean, one can think of others, like ethical wonder from the new Yorker and the magnificent writer and surgeon, but it is a rare combination of skills, particularly when that doctor is an oncologist who must frequently utter those words that no patient wants to hear you have cancer. So please welcome. [inaudible]

Speaker 2 (<u>02:20</u>):

Okay.

Ranjana Srivastava (02:20):

Ladies and gentlemen. Good morning. And it's my privilege to be here in Adelaide. I've never been to Adelaide before. It's a beautiful city and thank you for having me and thank you for waking up on a Sunday morning to be here. I had trouble getting here. As Peter has explained, I'm an oncologist, which is an adult cancer specialist. And my brief today is to talk about telling the truth, perhaps stemming from the title of my book, tell me the truth conversations with my patients about life and death. So telling the truth in the next 20 minutes or so, I want to illustrate what this means to me and what I believe it should mean to patients and the general community it's called her Mrs. Jones. She would be a typical patient that I would see. She is 76 and recently diagnosed with advanced cancer of the lung. She has had a prolonged recovery following thoracic surgery to remove fluid from her lungs, which was making her breathing difficult. The breathing slowly improved. And she came in to talk about treatment.

Ranjana Srivastava (03:23):

We discussed chemotherapy, which she was keen to try, despite the mentioned side effects. And she told me that she wasn't interested in dying yet and would do everything to beat her cancer. The first cycle of chemotherapy did not affect her too badly. And she felt quite Boyd. The second cycle landed her in hospital with all the toxicities. She had been worn to expect. She got out of hospital looking okay, but spent the next two weeks in bed, feeling weak and washed out. But our original intent to beat the

cancer remains strong. And when it came time for the third cycle of chemotherapy, she decided not to tell anyone about just how bad she had been feeling. She feared reasonably that no one would entertain giving her more chemotherapy if they found out the truth. So she went on to have a third cycle of treatment, which destroyed her.

Ranjana Srivastava (04:17):

Body's meager reserve. This time she was hospitalized looking moribund for three days. She was delirious, unable to recognize her own children, plucking at the air, looking at sorry, cell shell of her former self, however, resuscitated with antibiotics and fluids she improved. But the scans showed that her cancer had grown. In my estimation. She had only a few weeks to live. Now doctors are notorious for not getting the prognosis, right, but Mrs. Jones did look very ill. As I sat by her bedside on the first day, she could talk coherently. Imagine my surprise. When she asked me what chemo I plan to give her next, my first thought was that she was still delirious, but she was actually very serious. My reaction then was to be puzzled as to how the patient could be. So up to my next thought was to firmly stand part. The idea of further chemotherapy from her mind pointing to a recent near death experience, but it seemed odd that a reasonable and intelligent sounding woman would behave like this.

Ranjana Srivastava (05:27):

So I decided not to rush to judgment, but find out a little more Mrs. Jones. I said, what do you think more chemotherapy would actually achieve? Why? Of course I have a life to live. She responded looking at me curiously. So do you hope chemotherapy might help you live longer? Wanted isn't that why anybody has chemo? And this is the oncologist dilemma. How to tell the truth without extinguishing hope, how to tell Mrs. That her lifespan was limited. That further chemotherapy would be futile or even hasten death. And that her remaining days would be much better spent cherishing life than fighting off unnecessary toxicities. How to shine light on frankly, unrealistic expectations without coming across as I'm caring patients like Mrs. Jones abound in practice, many are shocked when confronted by the news that there is no other active treatment for their illness. Some claim that they had never been told this could happen.

Ranjana Srivastava (06:35):

Others, that they never expected this to happen to them. Many become angry. Many others become depressed. Family members commonly accused the oncologist of giving up. Once you said there was no other treatment, Jack dad just gave up and died a two year full daughter says whatever you do, I don't want you to tell her that things are looking that bad. A grief stricken husband implores. It is no wonder then that faced with such intense emotions and heartfelt. Please. Sometimes it seems easier to write up another round of treatment than have a somber discussion about life and death. But it's my experience that the vast majority of patients recognize it themselves when they are seriously or incurably ill patients are not fools. They notice their weight falling off the headaches, getting worse. The fatigue proving insurmountable. The term denial is commonly used in relation to patients who pretend to be better than they are.

Ranjana Srivastava (07:41):

But what I see is that many factors determine the readiness of a patient to accept or voice publicly what he or she senses privately. These factors may have to do with culture, religion, a sense of responsibility or a deeply held personal philosophy about how one ought to conduct oneself towards the end of life. But regardless of the circumstances I have yet to come across a patient who does not appreciate compassion, empathy, and honesty from a doctor during a difficult phase of life. So you might ask what honesty means for Mrs. Jones does honesty. You mean telling her bluntly that chemotherapy is a waste of time or that she should open her eyes to a poor prognosis. You might recall that the tote, but plenty of patients find themselves on the receiving end of blunt facts that terrify them and their loved ones. It causes them to lose what little hope they had.

Ranjana Srivastava (08:46):

And long after the patient has gone leaves relatives with a lingering sense of despondency over whether things could have been done any better. My feeling is that faced with the plain facts. The feisty Mrs. Jones would explode with anger, although privately she would have been crushed. So I think that honesty must be tempered by that other vital quality in medicine, which is empathy. Empathy is the art of putting yourself into another person's shoes to imagine what it must be like for the patient to be going through the experience. Empathy is difficult, although not impossible to cultivate. And when time is short and cues of patients longer than ever, it gets even harder. But what Mrs. Jones and patients like her need in place of chemotherapy is empathy. They need their doctor to say, I can see how eager you are to keep fighting your cancer.

Ranjana Srivastava (09:49):

But let's talk about how I can really help patients want the truth from their oncologist. Some want the whole truth while some are satisfied with parts of the truth. One patient likes counting the exact number of spots in the liver. Another one's the facts in broad brush strokes. One may want to understand what a 10% survival rate really means. Another is just contempt to know whether he will be around this Christmas. One wants to protect her pregnant daughter from the bad news. Another chooses his son to be his only filter. If I had thought in my younger days that there was only one kind of truth. What I see clearly now is that even truth comes in different shades. Part of the obligation of being a doctor is to build an understanding of a patient so that the truth can be tailored to the individual.

Ranjana Srivastava (10:48):

This does not mean bending the truth online, but I also don't feel a compelling need to make a reluctant patient and expert on their diagnosis or their prognosis at the same time. If it is what a patient wants, a doctor should be equally happy to discuss the latest newspaper article or journal publication about their illness. My overall view is that by keeping an open line of good communication and letting it be known that you are approachable, things tend to work out in their own time. So what happened to Mrs. Jones? You wonder one day she asked her ever present family to step outside of the room and allow her some privacy. She told me then that our sole aim in life now was to see her first grandchild get married in six months time. Would that my saying anything further she added, but I'm beginning to think doctor, that's not going to happen.

Ranjana Srivastava (11:49):

Her grandson had told me privately that he would do anything to have favorite grandparent present at his wedding, but just didn't see a way to broach an earlier wedding with grandma without implying that he thought she was dying. It soon became clear to me that not only Mrs. Jones, but her entire family quietly realized the seriousness of her condition. There were all worrying privately, but no one wanted to be the first to speak out. Sensing that Mrs. Jones had arrived at a point where she was willing to discuss the inevitability of her decline. I took the opportunity to praise her for her courage thus far while saying that the next part of her journey required deeper courage and conviction. So she asked me what I

would advise. I had no hesitation then in telling her that from everything I knew about her, she should not have the chemotherapy.

Ranjana Srivastava (12:48):

But think about what the most meaningful way of spending the rest of her days might be. Was it a sad conversation? Yes. In part, but a necessary one. And I firmly believe that it's a conversation that no oncologist can shy away from. It was also empowering for the patient who now finally felt able to make a decision that was in her best interest. After a Frank family meeting, Mrs. Jones went home to preside proudly over her grandson's wedding, which was brought forward. Her final wish fulfilled. She signed an advanced care directive, which meant that the next time she fell ill, which was less than a month later, she received no heroic measures, but was allowed to die peacefully. Her family had always been apprehensive about how the proud matriarch of the family would cope with the inevitable decline, but they were filled with relief and gratitude for the way things ended.

Ranjana Srivastava (13:53):

The last time I spoke with them, they were pleased that she had managed to recover some quality of life. In the last few weeks, there was a common feeling both inside and outside the medical profession, that good communication skills, empathy, and compassion towards patients are intrinsic skills. And they can't be taught. This is true only to an extent, and there is now good evidence to suggest that in fact, these skills can be taught and honed much in the way as doctors learned to do procedures. In fact, medical students and doctors are keen for this type of education because they recognize that their job satisfaction is derived from their patient satisfaction. The best medical schools and hospitals around the world are recognizing this brief propelled by the voice of communication is in curbing complaints, reducing legal action and improving patient experience of care, finding ways of telling the truth and explaining sophisticated tests, treatments, and decisions are all going to become crucial in the coming years. As modern medicine crosses once unimaginable frontiers and a crucial measure of how healthcare system will be, how well it can demystify medicine and communicate with patients.

Ranjana Srivastava (15:36):

I would like to say that I don't consider myself an expert or the only voice on telling the truth in medicine. I make mistakes too, and hope that I learned from them. I also know, and respect plenty of skilled people who handle difficult situations, tragedies, and give bad news routinely while retaining the admiration and loyalty of patients and their families. But what I do see as a common thread between all these people is that they regard the practice of medicine. As more than a job, they regarded their vocation. And if your vocation is to first do no harm, you will always be looking for better ways of telling the truth. Thank you. [inaudible]

Ranjana Srivastava (16:42):

Stand. Yeah.

Peter Mez (<u>16:46</u>):

Is all suspend out here. Now I have plenty of questions for us on that, but I wanted to give you an opportunity to start asking questions first, if you'd like, let me ask one, and then there's a microphone there and I'll invite you to go to the microphone, the middle of the room. If you'd like to ask a question or if it's too difficult to get to call it out and I'll, re-ask it so everyone can hear. So Rhonda, my first

question you talk a lot about the difference between cure and care and how a lot of medicine is focused on cure rather than care. And I wonder in the contemporary medical system, whether there is time for the care part, whether, because the sort of conversations you have with people, they don't happen in five minutes or 10 minute Medicare

Ranjana Srivastava (17:32):

Concept. No, no, look, I agree. And it's a good point, but I think that care just has to be an essential part of medicine. And what I find is that if you take the time, once it's moves the passage, all those other times, so a purely sort of a very basic way of looking at it is if you give the patient time once or twice and explain things properly, all the other appointments take less time. That's a, that's a very crude way of looking at it. But I think, you know, people come to a doctor for, for care as much as for cure. And, and I think that the excuse that there is not enough time you can only use so much. And I think medicine and doctors have to find the time. And, and it's not necessarily the quantity of time as well. It's also the quality of time that you spend in those eight or 10 or 20 minutes with the patient,

Peter Mez (<u>18:28</u>):

You give examples in the book of the hats from earlier in your career where you, you didn't get that time where you actually, when the patient was trying to tell you something, you were trying to avoid the conversation. I think that's the case. Absolutely.

Ranjana Srivastava (18:43):

And you know, you, you think you're doing the right thing because all your, all your medical life, you were taught about treating disease and dealing with disease, and you spend so much of your training, learning the chemotherapy regimens and learning drug names and details. And, and it's interesting. Now I say to my trainees, you know, you can actually look all that up. And so what you do need to spend time on is developing your communication skills and actually listening to what the patient has to say. And then, you know, as I said, we all learned from trial and error and, and I think that we do need to get better at spending quality time with patients

Peter Mez (<u>19:23</u>):

Questions. Yep. Okay. We'll have one here.

Speaker 6 (<u>19:27</u>):

Thank you for your empathy and compassion. I'm from cancer voices, south Australia, which is a consumer group. And we often hear about bad news delivered badly. And many of us as patients would like to be able to give back to the system and help make positive changes as a result of their experiences. Can you see a way that PA patients or cancer patients can talk about their ways news has been delivered badly and perhaps help the clinicians and learning clinicians to be able to learn their craft a

Ranjana Srivastava (20:03):

Little short? I think, I think voices of patients and, and through organizations like yours are incredibly important because after all the health system does respond to patients complaints and to patient's voices. I mean, look at the surgical waiting list is a classic example. Every week, there is somebody on the radio complaining about waiting for the hip replacement, but there isn't anyone on the radio

complaining about how they were treated by their oncologist or GP or doctor necessarily. And I think if there is a real voice in the community saying that there does need to be more empathy and more quality time. I think, I think it will filter down. And perhaps, you know, that a day will come when doctors are remunerated appropriately as well for spending, you know, not eight minutes with the patient, but 20 minutes, part of the reason GPS spend seven or eight or 10 minutes with the patient as opposed to a specialist.

Ranjana Srivastava (21:01):

I mean, I do have the luxury of spending a bit more time with patients. And I couldn't do this in eight minutes, is, is that there's pressure on funding. If, if Medicare only reimburses so much, then everybody feels the pressure to keep moving and then patients get churned through a system. But I think it's, and the other thing that medical schools sometimes do is bring out oncology patients to speak to medical students. And I think that's a really powerful way of inculcating in students and training doctors early in their career. The importance of good communication and the lasting impact that poor communication has on a patient. So well done just

Peter Mez (21:41):

Before we take the next question, they'll just sort of follow up is that aspect of training improving because I took from your book that in your training, that was a very small part. The communication with patients was like, you know, a couple of afternoons in the course of your six year medical degree,

Ranjana Srivastava (21:58):

It's look up. Unfortunately it still seems to be an optional extra in most places as I see it, I think it is. I think the understanding that it is important is improving, but to implement it practically, I mean, you know, you will still find a preponderance of scientific subjects being taught in medicine. And I think there has to be a realization from the very top downwards that actually teaching people how to become better doctors is as much about teaching them to become better people. And I think that's still lagging.

Peter Mez (22:30):

Okay. Question here, I'll take this one. And then you said it's partly for the recording. So if you don't mind, yeah.

Speaker 6 (22:45):

A very brief introduction. I mean, I'm of an age now, I'm likely to be given bad news and having to give people bad news. But I worked as a doctor in Medicaid and remote and rural areas for much of my life. I think it makes it much easier if you are an old fashioned family doctor and you know, the whole family and you've seen the person, you know, delivered their grandchild, possibly, you know, that sort of thing. The other comment I'd make before I ask my question is that I, for some reason, I've never been afraid of death. The mode of dying is a bit of a worry at times, but I think if you're not afraid of death yourself, it is much easier to discuss the matter with your patient in an empathetic and understanding way. I think those doctors who are terrified who see death as failure on their part, find it much difficult. That's just my suggestion. The question I have is this is what really bothered me. I didn't worry too much. If I had to tell somebody the bad news, I mean, I felt I could do that. What did bother me is when the relatives demanded that I didn't tell the patient the truth, and that puts you in a very serious ethical dilemma, especially if you yourself thinks that the patient could cope with it, the person who's not coping with it, of course is a relative.

Ranjana Srivastava (24:17):

And that's a, that's a very common scenario. And, and especially in, in multicultural Australia now, and I work in a, in a very multicultural area where we get people who strongly believe that patients should not be told about their diagnosis because they will die quickly. Interestingly, I mean, I sort of, I started off as a trainee, I must say by saying to relatives, well, no matter what you think I'm going to do it, which didn't, which backfired and it doesn't work and it's an inappropriate way of doing it. I, I realized but I think asking relatives why it is that they don't want the patient to know. I find works for me most of the time, because often it comes back to sort of root fears that relatives have, for example of say they fear that I will tell the patient that they only have two or four or six weeks to live, which obviously I can't, because most of the time doctors are really bad at prognosticating.

Ranjana Srivastava (25:14):

But dealing with some of their fears and anxieties about why they don't want somebody to know helps them feel heard because often what relatives here, all along the medical corridor as well, it doesn't matter. It's the patient's right to know, and that's not what relatives need to hear because I think they realize that it is the patient's right to know. And by and large relatives are trying to do the right thing by protecting their family member. But I find that what works for me, and it may take more than one consultation is explaining to the family, to the relatives, why it's important for patients to know. And, and one tragic story that plays out time and time again is when a patient doesn't know they come into the emergency department and of course everyone tells them, so you have cancer. So where do you have cancer?

Ranjana Srivastava (26:01):

And the patient says, what do you mean I have cancer? And I relayed this story to relatives and they see this there's truth in it, or, you know, a palliative care nurse or some nurse goes to visit them at home. You can't put in services into place without having the patient know what they're being treated for. And, and I do find that thinking back over the last couple of years, most, almost everybody has eventually come around, but it takes a process of explaining to them why it's important rather than sort of the medical paternalism. What is the doctor patient relationship? And the patient has to know, and that's the end of it. Does that sort of make sense?

Speaker 2 (<u>26:47</u>): [Inaudible],

Peter Mez (<u>26:47</u>): I'm

Mr. Goodfellow (26:47):

A public health patient. I went to my GP in 2008 and I was misdiagnosed. I was told I had the flu. I went back a week later, vomiting on the footpath at eight 30 in the morning and said, what about this lump in my neck? He said, no, it's very virulent flu. And he said, it's a bunched up muscle. And he said, continue taking the Valium tablets to reduce the swelling. And I'll give you some sleeping tablets say that can sleep two days later. And I was staying around and staggering around the house. I was scared that I was going to fall downstairs. I drove myself to a public hospital. I waited five hours before I got into see a

doctor. When he did see me, I hadn't shaved for 10 or 12 days. It was a heatwave. I had a pair of shorts on a pair of rubber thongs and the blue singlet.

Mr. Goodfellow (27:39):

I was told to go home, have a shower and a shave and go and see my GP in the morning. I told the doctor that if he didn't look at me in the next three minutes, I'd knock him unconscious. And a little Burmese doctor that had been standing alongside me, who said, who looked at me initially and said my English skills. Aren't very good. I'll get a senior doctor. When this doctor who I threatened, walked away, the little Burmese bloke said, I think he understands. He then came back and did what he should've done in the first instance and got a tongue depressor and had looked down the back of the throat and sent me for a CT scan. Two days later, I was then admitted two days later, one doctor around about the same age as you came to the end of my bed at eight o'clock in the morning and said, good morning, Mr. Goodfellow, my name is doctor with Allah. I'm here to tell you you've got cats and you've got one to five years to live. Do you have any questions?

Mr. Goodfellow (28:39):

I pushed myself back into the pillow and I thought, this must be a dream. I'll say, could you repeat yourself? And she did verbatim following my little outburst. I was asked to leave the hospital, which I did six weeks later, I went to the Royal Adelaide hospital and they told me that Dr. [inaudible] Was, the person was going to operate on me. And I said, she won't be coming near me with a butter knife, a little and scalpel. They said, your Republic, patient. You'll do what you're told. I said, I don't do what I'm told. They then went and got a guy Reese who came out and came into the room and I repeated my story to him. And he said, she'll be spoken to, he said, you shouldn't have been talked to like that. And he said, I'll look after you personally. And he did the major neck dissection on me and subsequently put in a prosthesis because my voice box was moved on that side. Do you run any seasons in Adelaide talking to [inaudible]?

Ranjana Srivastava (29:47):

Firstly, I'm really pleased to see that you're, that you're well, and that, then that you're here and thank you for that contribution and jokes aside. I think it's, it's tragic and it happens a lot. And I think we just need to get it right and get it better. And people like you who sort of name and shame are actually quite important in the system, because most patients just sort of swallow all this and sort of package it into the bad experience related to cancer. And I think although cancer may be associated with a lot of bad experiences communication, shouldn't be one of them.

Mr. Goodfellow (30:26):

Can I check the opportunity to be in opportunities then and say that I have written about my experiences too. And the book is called waltzing with Jack dancer, a slow dance with cancer, which is a book of poems by myself and a short story by my daughter.

Speaker 2 (<u>30:44</u>): [Inaudible] The

Peter Mez (<u>30:45</u>):

Last, last bit was published by Wakefield press in case. Can I just follow up from I'll come to your pitch at the moment, but it seems fun to know that often it, there is a, I don't want to bad mouth surgeons, but it does seem to be that there's often a disjuncture between what, the way a surgeon deals with the cancer and the way an oncologist might approach it. Just as a game going on on the stories you tell in your book.

Ranjana Srivastava (<u>31:11</u>):

I think, you know, I think surgeons are trained to operate, to remove stuff. And this is their entire, if you look at a surgeon's law book, it's all about how many operations they have done, how many hours they have spent in the operating theater with an anesthetist patient. And really there is no room in their training right now for them to learn about the very important skills of communication and empathy and, and talking and listening. And you know, it's, it's an uphill battle because I suppose as, as I often say, you know, when your life is in the hand of a surgeon in the hands of a surgeon, you don't really care whether he's smiling behind the mask, which is true. You just want them to do a good job operating, but surgeons are often at the forefront. You know, they get in, they come in to see a patient like you before we even get wind of the patient.

Ranjana Srivastava (32:07):

And this is exactly the sort of conversations that happen at bedside often before even eight o'clock is a good, is a late time for a surgeon that happened at six o'clock in the morning. And, and, you know, in my hospital, certainly I'm I'm trying to teach the plastic surgeons and the, and the other surgeons to, to talk to their patients. But I think I do sense a change. I think that the newer generation of surgeons is realizing that it is so important to talk to patients. I had a young plastic surgical training other day, and and she was talking about a lopsided mastectomy, a lopsided breast reconstruction that had been performed on a breast cancer patient. And she said, how terrible she felt when the patient said to, to her, oh, you know, you've, you've done this reconstruction, but you know, it looks terrible. And so the, the six year old sort of white male surgeons at all have rubbish, you know, it's, it's just fine and it'll get better. And she said, and I stood there and I just knew that that wasn't the way we should be talking to her and that she had a point, but this is what my boss was saying. So, you know, what could I say? But I hope that when this young trainee becomes a surgeon herself, she will listen to a patient small because I think she was truly affected by that consultation. Okay.

Peter Mez (<u>33:26</u>):

We have another question there. And then

Speaker 6 (<u>33:31</u>):

Just a bit of background, I'm actually an oncology nurse of about 30 years. But I'm also at the pointy end of breast cancer at the moment. And so I could actually say lots of things here, but I think probably one of the privileges I've had at the end of my nursing before I gave up 18 months ago was I worked on a helpline. And that I think was the most rounding off sort of for my career, because I remember when I was at the Royal Adelaide working with a surgeon, I was a 23 year old and he'd seen about three people and he hadn't looked at any of them when, you know, he was, and I thought I had it back to a bit like a desk there. Anyway, he all of a sudden he looked around and he said, where's the next patient?

Speaker 6 (<u>34:24</u>):

I said, I'm not putting money in. And he said, why? I said, because you haven't looked at the last three. So I think it's that the, the comment I'd like to make is they need to be present. They need to have the attention to now. And that's, what's so important. And on a health plan, you can't do anything else. If you're going to do it properly, you have to listen to what the story is. But I think it's also that, that ability, I mean, it's the 23 year old, I was absolutely myself that I could actually even do that to this guy, you know, cause he was a surgeon and oncologist and he just stopped and looked at me and then the next patient, he actually turned from the desk and actually spoke to them. But it's that, you know, the old fashioned way of they'd sit at the desk and it wasn't any, it wasn't welcoming. It wasn't, you know, he, I mean he had a million things on his mind. You can tell and

Ranjana Srivastava (35:21):

You probably remembered that encounter for the rest of his life. I would say because not many people would say that to a surgeon. That's right.

Peter Mez (<u>35:29</u>):

Can I just ask you about the helpline? Just what, what form does that take? People might be interested.

Speaker 6 (<u>35:33</u>):

So cancer helped line up the cancer council. We're all now trained oncology nurses or have some training in oncology and we're not allowed to give advice. But what we do do is tease out what people are actually ringing about. Cause somebody will ring, you know, a young woman will ring and say, I want to know about a week, but she's actually got an absolute, you know, she suddenly burst into tears and said, well, actually that's not why I'm ringing. You know? So, but some of them that is all they're bringing about. Don't get many men, I think it's predominantly women re either ringing about their husbands or themselves or helping their friends, et cetera. Mm.

Ranjana Srivastava (36:18):

I mean, I think cancer support nurses do it, do a tremendous job as do palliative care nurses. I think however, that it's really important for doctors to come into that field and actually engage with patients and not leave it only to nurses and support services and social workers, et cetera, which is, which is sometimes the risk that that, that you run in oncology is, is the oncologist sort of things. Well, if I can just handle the chemotherapy part of it and I can outsource all those other things to other people who may be more qualified,

Peter Mez (<u>36:56</u>):

Outsource

Ranjana Srivastava (36:56):

The emotional sort of stuff. And I think you'll find plenty of doctors saying that and doing that because they feel that this is their area of expertise, but I, I personally don't buy that because I think if you ask any cancer patient, they want their oncologists to be involved on the emotional side of care as well. Not, not just the chemotherapy orders.

Peter Mez (<u>37:26</u>):

The point was just being made that in remote areas, you don't often have those support services. That would take the question here. Can you go to the microphone please?

Speaker 6 (<u>37:38</u>):

So it sort of leads on a bit from what was just being said, really that doctors don't work on their own. And so I was interested if you would talk a little bit about working with the team, because that seems a really important part of it as well.

Ranjana Srivastava (<u>37:51</u>):

Oh, absolutely. And, and, you know, no oncologist can or should work in isolation and you couldn't, you couldn't do a good job with a patient in isolation thinking that you are the expert on everything. So a common oncology team would involve a senior nurse. So like a nurse consultant or a supportive care nurse, kind of a role very often a palliative care nurse. Social workers are really important, physiotherapists occupational therapists. So, so, you know, they are all, they're all important and vital pieces of the sort of puzzle really. And the oncologist is very much just one part an important part, but, but just one part. And so I think it's, it's, it's important not to overestimate the importance of, of a doctor, but but play players a team player. And I think most of us do realize that, and I'm really grateful for it. I mean, I couldn't do my job if I couldn't send a dozen patients to the social worker to sort out. So yes, the team is really important and I can't speak highly enough about community palliative care, who I think shoulder a great burden of communication and care in the community. I'm a big fan of them.

Speaker 6 (<u>39:16</u>):

I wanted to talk about when a patient loses power through dementia, what happens then? How do you, how do you operate in those settings?

Ranjana Srivastava (39:26):

Okay, now that's a, that's a really good question. And I think it will become an increasingly relevant question as our population ages. So, I mean, I could, I could go on about this, but fundamentally when you are sort of hypothetically say you were faced with a truly demented patient who has no decision-making capacity, I think it's very difficult because in general, you would want to shy away from any toxic toxic treatment, no matter what. And next of kin or a relative says, or even if they have, you know, a medical power of attorney, et cetera, because I strongly feel that, you know, chemotherapy is toxic stuff and the person who is receiving the chemotherapy needs to know what's going on and, you know, the best minded, the most good intention relatives in the world and husbands and wives in the world can't really speak for a particular patient for an individual patient.

Ranjana Srivastava (40:23):

So I think with the demented patient, I think first do no harm. So, you know, if it is something recently, we had a demented lady who was found after several weeks of living alone in a really disheveled state brought into hospital. And she had an obvious facial tumor, in fact, a skin cancer that had overgrown and it was bleeding and it was infected and it was in a terrible state. So we could clean it. We, we debrided it without taking her to theater because we couldn't get her consent. And she had sort of some radiotherapy just to dry up the area and all of it was fairly minimally toxic. And then we decided that that was all we were going to do. If she hadn't been demented, she would probably have gotten, she was very wasted and weak and all the stuff that goes with living alone and uncared for you would, if she

was well and, and, and fed, you would have taken her to theater, debrided it properly maybe thought about plastic surgery reconstruction.

Ranjana Srivastava (41:21):

So I think dementia patients do have to be dealt with differently. We get a lot of demented women with breast cancer. And often the breast cancer is not such a big problem, but has found a lump while washing them or bathing them, et cetera. And sometimes you don't need to do anything about it either. It, it all depends on the situation, but I do think that major surgery, major chemotherapy anything major that you're doing with the demented patient has got you need to think very carefully, perhaps if it is important, involve the, the hospital medic ethics team or the law, the, the lawyers to figure out exactly where you're heading. Yes, please. I just wondered if you could

Speaker 6 (<u>42:09</u>):

Talk a little bit about hope futility and truth-telling in clinical trials.

Ranjana Srivastava (42:16):

Wow. So yes. I mean, clinical trials are a, they're an absolutely important and fundamental part of medicine and the drugs that we are getting today that treat cancers and that even cure cancers, all of them started with clinical trials where they were tried on rats and Guinea pigs. And then somebody was asked to put up their hand and say, well, there's this experimental thing that's going on? Do you want to take part in it? So I can't overemphasize the importance of clinical trials in their own setting. However, the average patient has a very different understanding of a clinical trial. And this is where perhaps the problem that you are alluding to clinical trials and in particular phase one trials, which are the initial trials in humans have essentially a less than 5% chance of helping the individual patient. There are trials. And the word trial is, is, has meaning it's an experiment.

Ranjana Srivastava (43:17):

The point of entering that experiment for me, or for you as an individual patient, is to help future generations. It's for altruism. It's not to help you. People don't realize that when they enter trials and a lot of people actually think commonly, you would enter a phase one trial after you have failed several lines of standard chemotherapy. So you would have, you know, 1, 2, 3 or four lines of chemotherapy that, that the general population gets, things are not working. And the oncologist says, well, there's this clinical trial running at, you know, usually at a big center, such as Peter MacCallum in Melbourne. And the patient says, oh, here's another chance for a cure. When all this stuff hasn't worked, this is where dashing of hopes comes in, because what it is is a trial to say, well, you may benefit from it, but the chances are, you know, one in a hundred, maybe if that, so what happens is when people fail those clinical trials, because inevitably their disease progresses as it was supposed to because it's an experimental drug.

Ranjana Srivastava (44:23):

Still people feel cheated. They feel as if we sent them all the way to this clinical trial, which was supposed to be this new drug that was going to cure them. And it didn't. So I think you need to be extremely careful as an oncologist about enrolling people in trials and understanding and helping people understand. Now, if you have ever been part of a clinical trial, the sheaf of papers handed to you is about this pig. The consent form is crazy. I don't know how any, you know, the plain language statement runs to 20 pages. I mean, when your mind is filled with all this other stuff, and when you're trying to

grab onto any last straw of hope what sign on it, of course you'd sign on it. Does it mean you understand it? No. There was a really good trial a study done in the states when I was spending some time at the university of Chicago that said that the average patient understood English at a grade three level. And this is the level at which a plain language statement should be written. Clearly it's not written at a grade three level. So so I think we have to be particularly careful. I think you need to, you need to support clinical trials as doctors and nurses and the general community, but we need to be aware of what it is that we are selling patients. Do we have further questions?

Speaker 6 (<u>45:51</u>):

Cancer helpline is a national number. And so people from rural and remote areas can access it. And the youngest person I had was an 11 year old Aboriginal girl who had, was being treated, I think for leukemia. And she, because they get so many brochures, she found this number and an aunt who had gone out of the house. So she decided she'd rang. And she was saying, you know, am I going to die? And just really simple questions, but it just goes to show that something like that can reach people who are in remote. Absolutely.

Peter Mez (<u>46:27</u>):

One of the things I wanted to ask about is the consistency of care, because what you talk about is so much the relationship you build up with a patient and the ability to tell the truth is partly based on, as you say, that initial interview, where you find out their family circumstances, you know, you get the personal history, as well as the medical history, yet that same patient may come back for their next appointment and they don't get to see you. They get to see someone completely different than the public system.

Ranjana Srivastava (46:54):

So, so yes, I don't know how things operate in Adelaide, but in most Melbourne public hospitals, you can see the same doctor. Well, not you can't, but you don't see, tend to see the same doctor in a public outpatients. And I think that this is a, usually a readily flick fixable floor, at least in oncology ad patients, because I think having cancer is different from having your appendix removed, where you can come back to surgical ad patients, see a different surgeon who can check your wound, make sure you're okay, and off you go cancer. Isn't quite like that. It's a gin. I know that some public hospitals deal with the issue by going through the list, having the doctors there and saying, well, I know this, this and this patient, so I'll see these and so on and so forth. And that sort of works.

Ranjana Srivastava (47:41):

I suppose, the reason that we don't have regular doctors in public outpatients is because most hospitals are teaching hospitals. And so trainees need an opportunity as well to see patients. And, but I think there are ways of getting around it because one of the frustrations that I know I share with a lot of my patients is this whole thing about seeing a different doctor each week. And it must be so frustrating to start a conversation with one doctor and have somebody completely different come along who may not be on your wavelength and so on, but this is the way we deal with it in our outpatient system to where we just try to see the patients we have seen before, or try to do the right thing by the people we know. And if somebody else is seeing a patient who we know at least try to brief them on it, but the system is far from perfect.

Peter Mez (<u>48:30</u>):

There's a, a story in, in, in, in your book about a man who you were seeing who was quite young, he was 58, he was active, but he got cancer. Non-Smoker non-drinker so all those unfair things that people feel with cancer and, and you were absent from work for a while. So he ended up seeing someone else. And what really devastated him was the fact that, that the other oncologist said essentially said, I won't make another appointment for you. You're, you know, you're dying your cases close. There's no point you're coming back. And the devastating effect it's had on him, which you ran into him in the corridor and saw him separately. It was like, just tell us a bit. Yeah. So,

Ranjana Srivastava (49:12):

You know, and, and it really demonstrated to me the importance of, and the importance people put on the reassurance from oncologists. So this is a man, as, as, as you described, he was he was a man who was really terminally ill. And each time he saw me, he, I made another appointment because I felt as if he felt reassured, knowing that some he could come and see somebody, it was like his safety net,

Peter Mez (<u>49:36</u>):

For lack of a better, he knew he was dying. He wasn't, he wasn't, you weren't giving him false. He didn't

Ranjana Srivastava (49:41):

Come looking for anything apart from popping in to say, well, this is how I've been in the last few weeks. And I thought that was a perfectly good use of my time. One of the issues with sort of discharging patients from clinic is because everyone feels pressured and they feel as if they have not, if they have nothing to offer, then the patients shouldn't come back. But I guess everybody has a different definition of what you have to offer. So what happened with this man is I'd been on maternity leave for some time. That was my first week back. He he went and saw somebody else. And I had been meaning to pick him up. As I alluded to before you try to see the patients you've seen before and ran into him in the corridor when I went to get another patient.

Ranjana Srivastava (50:23):

And he was absolutely devastated because the young trainee had said, well, it doesn't seem to be any particular need for you to come back in all good intention. And it's probably exactly what I would have done as a trainee. And he was devastated because he felt as if he had no one else to go to because his GP who was very good and very competent, he used to say, well, now that you have cancer, you're really in the oncologist hands, you know, they can adjust your drugs, they can manage your pain. And so he was in tears, this man who had been so brave and, and just so spiritual throughout his battle with cancer was shaking and devastated in tears, all because nobody gave him another appointment. And so I said, look, you know, come back. I want to see you. I said, no, but the other people said that there's no need to be seen.

Ranjana Srivastava (51:10):

And I said, well, you know, I just like seeing you, and if it made his day and he said, it was the, he actually said to me that that was the most fruitful appointment he had had in all his time that I said he could come back. And I thought, you know, all these things we have done for him. So it's a really sort of poignant reminder of the little things you do that change people's lives and he didn't come back. So, no, I know. And he actually, he died after that here, he was putting on his shoes and socks and being bad. One day he was sitting in bed and he collapsed and sort of died in a few seconds. It was the best way for, for him to go. And and his wife called me to say, he wouldn't be keeping his next appointment. So but

you know, to, and I, I remember him, I think of him very fondly. And I think of of course I still sit in that clinic. I still go through that corridor. And I'm often reminded of, of just how powerful that whole incident was.

Peter Mez (52:09):

And what about the issue of dying with dignity? When, what happens when someone comes to you and says, well, I don't see any point. You know, all I see ahead of me is pain. Can't you help me to end this faster.

Ranjana Srivastava (52:25):

So, you know, I mean, this is, this is an issue that every oncologist is faces is the issue of euthanasia and physician assisted euthanasia, which is of course prohibited by law. So I think you have to, as a, as a, as an oncologist, and I feel strongly that I have to behave within the confines of the law, but having said that, I think a lot of people wish to put an end to their suffering because they lose hope and they lose hope through sometimes through poor decision-making on the part of professionals, poor communication, empathy, compassion, lack of good pain relief, et cetera, depression. So I think there are many, many things that actually can be managed. And I'm not saying it works for every single person. And I personally see people who are as well-managed as they can be and, and really, they just want to die and they probably need to die. And in all honesty, when these people die, we all breathe a sigh of relief saying, I'm glad he went because it was the right thing. He or she for that person. But for a lot of other people, they want time. They want care pain, relief management of their anxiety, depression without feeling dismissed. And I think that helps us substantial. Number of people cope with life with cancer.

Peter Mez (<u>53:50</u>):

Yeah. We have time for one more question. Yeah. This is more of a comment speaking as a psychotherapist. If I said to somebody come back next week and I wasn't there and somebody else was there and that happened the next week after that, the next week after that, we'd call that malpractice. I think that's important because we're dealing with a psyche here, we're dealing with people and they need that sort of attention. It's part of the medical model. Isn't it?

Ranjana Srivastava (54:20):

Look, I, I mean, I see what you're saying, but I think that the public health system would probably not be able to cope with that pressure. So I think we also have to be re we have to balance idealism with realism and, and, you know, and, and although I see problems with the system, I must say that the majority of cancer patients in Australia actually receive world-class treatment. And I've been to several countries and spend time with several oncologists from different countries. And I think we have, we have something to be very proud of, not just in oncology, but as a system, as a medical healthcare system. Any list you look at, I mean, Australia does exceptionally well providing the care that, that we do.

Peter Mez (<u>55:05</u>):

I want to apologize. I don't mean personal malpractice. I mean, systemic malpractice.

Ranjana Srivastava (<u>55:11</u>):

I think, I think in a system, there are always things you can improve. And one of the things that I would improve in oncology is consistency of care. But if that's not currently available in a lot of places, I still think that a lot of patients, and I'm always impressed by how people managed to travel, traverse the maze of cancer therapy and come out the other end, safe and sound, which, which reassures me that even though we may not have the same doctor or nurse seeing a patient overall, we have we have teams of highly skilled and dedicated individuals who are looking out for the patient. And that's something to be really proud of.

Peter Mez (<u>55:50</u>):

Can I please ask you to join me in thanking rant?

Speaker 2 (<u>56:01</u>): [Inaudible].