

SYD – John Stubbs

Policy advocacy clinical trials and related issues. He is currently CEO of CanSpeak, a national volunteer cancer consumer advocacy group and sits on fifteen health related boards and committees at international, federal and state level. He is an Honorary Associate of the University of Sydney School of Medicine, an appointment recognising his work in clinical trials in this country. John has contributed to booklets and research papers as an associate investigator, edited consumer booklets for the Cancer Council and Cancer Australia and contributed to government policy on cancer, cancer services and the value of consumer involvement. Please welcome John.

Thank you very much for the introduction and for the opportunity to speak to you today. You will note that Karen and I are dressed very similar, that's serendipitous I think but it is about blood and so I think red or tangerine does have a high profile in what we do.

As I said, blood is very, very dear to my heart having had chronic myeloid leukaemia, so I've had platelets, I've had blood transfusions, I've been through the whole process. So I'm delighted to be able to give you my thoughts and also not only patient but carer and family input into this discussion because somebody is diagnosed with cancer you only don't get the patient you actually get their family and what that means to them.

So I think in relation to cancer, in 2000 there was a seminal agreement in Paris, on the 4th of February, which has now been designated as World Cancer Day. But I think what was decided there and what was agreed to there can actually be translated to many other medical conditions. I think there are over seven charters but I think the important one was the parties further pledged to advance universal recognition of informed consent. The process by which patients are fully advised of the purposes and benefits of any clinical intervention. That was signed by the Minister of the time, Woolridge, the clinician and it was the first time that clinicians, government and patient groups got together.

Professor John Seymour, who's head of haematology oncology at Peter Mac and Lyn Swinburne who set up Breast Cancer Network in Melbourne. So they were the Australian signatories to this document and it also went on to say the medical research industry, government and policy communities were regarding informed patients as key strategic partners in all aspects of the fight against this disease but I am sure we can put it to other areas as well.

I think setting the scene. The health care system should first and foremost be organised to meet the needs of patients. We are the centre of this. It is our disease. You are partnering with us, you are respecting our disease and engaging with us to make sure that we get the best outcome through all the treatments. This is very important because at diagnosis and I think Karen hit the nail on the head, my wife and I made a pact that she would come and attend every meeting with my haematologist at that time. And just as well we did because we heard different things. It is so interesting, I would walk out of there and say "oh well I've got this covered". And she said "Joy didn't say that". And I

said "yes, she did", "no, no, no she didn't". So we'd go back and speak to the haematologist and she said "John I didn't say that".

So that's really, really important because you've got this anger in you, you've got this fear, your prognosis in my case, it was three to five years. There were new drugs around, there was Gleevec which was on the scene. But, I would possibly not have been eligible for it. So you have this feeling at diagnosis, you've got this fear. It's like being before the judge and he brings the gavel down "you're sentence is three to five". You have these questions that you can't answer and you know that that's going to have an impact. "Why me. What have I done to deserve this"? I didn't know a lot about health or diseases. I was a professional footballer, I've never had health issues before, so something like this came right out of the blue and it's an age related disease. Family, how would they cope? I had three sons.

One son, who is the big tough, the elder boy, he just broke down. He was jelly for a couple of days. The other boy was strong "how are we going to get involved. How are we going to do this. What can I do. How can I get involved with the health system to try and make things better"? And so with all of those things you enter the unknown. You enter something which is totally new to everybody and you do realise that your life is not, you give your life over to a health system. It could be the clinician, the nurses and everything that the health system's got to offer. You've got these periods of incoherent feelings. I'm or was, a particularly confident person but your head is spinning. All of this has come to you right out of the blue and then you reach that crisis point that something is really wrong with me.

You've got to go through the whole issue. They start from virtually the day you were born to find out about your health. My mother had died, so there was some possible gaps there. And because you're part of the system and you're called back into the system "you've got to give blood" and you really understand that something is wrong with you and how do you cope with all of that? There is a crisis stage. You've got to go through all of these things. We looked at how much money we owed, we looked at funding, we looked at what would happen in this situation, we developed a power of attorney. That reminds me, my wife's still got the power of attorney over me. Maybe it's time I review that.

Those things are very important. You've got this illness identity, people and possibly they don't but there's a perception that they look at you differently. I was on a drug called Interferon A, which is not a particularly good drug, so from about 8.30, 9 o'clock I was out to it. So we didn't get invited out anymore, your social milieu changes. You put a lot of that onto the clinicians and you put a lot of that on to the health system because this is what's happening with me. You're a part of me, I'm a part of you and you've got to take this on. And that's through these constant trips to the medical centre. And you do enter, it's a medical, health minefield. There's chemotherapy, radiotherapy, haematology, oncology, cardiovascular, all of these terms that you had no idea existed until they're thrust upon you. What do they mean? All of these things.

So you go looking for information. What can help? As Karen said, you've got to use a language that we understand. A lot of people are very visual, so if you use bright colours, you use circles, you use numbers, diagrammatically, people understand "yes of course. I do understand that". You've got to recognise our

situation but also that of the family as well and the carer. I think this is where a general respect for each and everybody whose part of the health system and the patient, comes to the fore and I think that's one of the things that I can say through my treatment, there was a mutual respect with all of us and I think that helped in my outcome. Julie she would be the bad cop, so that nothing could actually come back onto me. She would be the intermediary if she felt something wasn't going particularly right.

So it wasn't about me totally, it was about the whole family and how they would cope. I think acknowledging where we are in this journey and I don't like the word journey but where we are together in this process. I think reinforcing it and just doing simple things like thanking the patient for being on time, thanking the staff for doing this. We ran a café and a catering business and there's always a lot of staff turnover in the hospitality industry but we had the same, we had two chefs for over four years and we had six staff and when we sold our business before I had my transplant, one of the questions I asked them was "why have you been loyal to us"? And they said "you thanked us".

And I remember every day when the chef would leave and I would just say "thanks Chris. Good job today" and people remember that. Just thanking, that's respecting what they do. It might be a cursory thing but that's important. I think recognising that you have a chronic disease because you're going to have all these trips back so you build a relationship. My haematologist and I have a 14 year relationship, a lot longer than many relationships today. I think the referrals are very important and that's referral to other clinicians, other members of the health system and again I think, I can't stress enough, involving the partner, the carer or the family in this whole process because they're with you, they want the best for you, they need to understand what you're going through.

They need to understand what the health system, the members of the health system are like. One of the things that helped me during my treatment was I had photos of my family all around me and I've got a very good looking son who was classified as "eye candy". So when he visited me there was a revolving door of nurses coming through and he was sick for five days and of course, my interaction with the nurses during that five days, you could graph the way it dropped. So he was an important element to the staff, he was also an important element to me. They're just little things but all of those add up to good outcomes for the patients.

I think what would good look like in this system? We do need a full treatment pathway. You do need your protocol. You need to understand it and the people who are visiting you need to understand that because on certain days you can look like absolute crap, excuse the language but on other days you're really up, so there's got to be that balance. Engagement. Access to information for decision making. That is really incredibly important as you move through your health and the health system environment, you do need that. Good care coordination I think is important. And also the transfer. When you leave the hospital scene, the transfer between the providers and the institutions and the engagement of the GPs, that is all very important, so if everybody's got that information along the way, it is good for the patient and it is good for the family. It's also good for the hospital because if they're up to speed on that, you're not going to go back into hospital.

Post treatment guidelines and information. I think that is very, very important. One of the issues that I had with the health system was around food and especially having chemotherapy, you lose the taste for foods and things like that. As a result, my wife who is a nutritionist, wrote a booklet for the Leukaemia Foundation called 'Eating Well' and so information like that and that's become one of their biggest sellers, people want to know when their foods change, just what foods they can eat and what are nutritious foods.

And again, this mutual respect, I can't stress enough. I have incredible respect for the health system in this country. I do some work with the National Institute of Health in the US and I am so glad I got sick in this country.

So the patient journey. I'm not a great Frodo supporter but I think it's very important. "It is a dangerous business going out on the road. You step onto the road and if you don't keep your feet, there's no knowing where you might be swept off to". And to me that's so important. If we've got the information, we are given the information, we can all share in this information, patients are really prepared to take that step. So I think that sort of sums it all up as far as I'm concerned, as a patient who's been through the health system. Thank you very much.

Questions for Karen or John?

Where do you think the greatest deficiencies are at the moment (14.20)?

Look I think the consent form is the real issue. Please leave consent forms at one page. That's all we need. A page which points out exactly what's going to happen, that is understandable, you can use some diagrams on them etc, etc. But to me once you turn over the page and start reading more, most patients are probably going to say "no". We just want it very succinct and leave it at that.

And I think a verbal conversation that accompanies that is equally as important.

I agree.

Questions?

In fact, I mean I think most people are gobsmacked (15.23) presentation and on behalf of everyone here John and Karen, thank you.