

Pain - Communication and the Patient Experience

Resources - Video 1

It's very helpful, as a patient, if you are acknowledged - by a kind word or comment, a hello, eye contact. And it's because you're at your most vulnerable; you're at your most frightened; and there's a power balance that's completely unequal in healthcare, and understandably. So when there is a response that's directed to you, it makes you feel as if there's a bond between you and the clinician, and that is worth its weight in gold. It doesn't mean that you're friends, or that they ask about your granny or, you know, what you had for dinner, but it does mean that they're relating to you as an individual as opposed to a caseload. And that makes you a better patient, you know, it makes you feel more part of your care. I mean, it's not to the extent of 'nothing about me without me' but it does involve you in a way and make you feel that there's more than just the clinical expertise you're getting. You're getting care, and care is more than just a great operation. It's a whole lot about how you're treated as a person, as a full person. And it's the simple things; it's not big stuff. The big stuff, the clinical care, is fabulous - do it! But it's the little things; it's a kind comment, it's a smile, it's an expression of interest.

I remember going in for one of my treatments and the doctor said, "Wait - before we start, how are the wedding plans going for your daughter?" - and I felt so good because he didn't just see me as his next, you know, dot on the line. It made a world of difference. Everybody who goes into healthcare goes in for the right reasons: they're idealistic, they want to help people, they want to use their intelligence and skill to make a difference in someone's life, and that's very heartening. But what happens along the way - and I think that they are trained in this, I think there are wonderful programs to help them with this - but I think the administrative overload, the pressure of time, the pressure of people... And I sometimes believe it has to do subconsciously with keeping some kind of a barrier between them and the patients so that they don't emotionally get sucked in to every bit of the things that are happening to others. I mean it must be devastating on some days. I used to work in communications and whenever we had a flurry around a terrible press release with a spelling mistake, and everybody would - I'd say, "Whoa - no patients died on our table. Let's put everything in perspective."

So along the way from the idea of being in medicine and the training to be in healthcare, it gets buffered out - not for everybody, but for many people. And they are busy, so they're too busy to look up and they're too busy to make eye contact, and they're too busy to acknowledge you, and it's really such a basic thing that you're asking for as a patient. It's like the triple As, you know: Acknowledge the patient, Ask what they need, and then Act on it. And as long as you're acknowledge in almost every area of healthcare it will make a difference.

I've been in waiting rooms, and they don't call it a waiting room for nothing, and I understand that, so I expect I will wait. I don't expect I'll wait four or five hours for an appointment that's been set. But what is fascinating to me is during that experience I watched the whole group of people, the whole society of that waiting room just furious and upset because they were backed up literally by five hours that day. And I was struck by the fact that the administrators sitting behind a glass wall could have and should have come out and said, "We're really sorry. Something has happened, we've had an emergency. We understand; we didn't mean to do this to you; it's your time as well. Have a coffee." Anything, rather than having everybody in the office come and yell at them. And by the time I got in to the examination I was sitting in the exam chair. And it was an eye clinic so I was looking at the wall. And the doctor came in, 5 1/2 hours late, said to me, "Read the sign." She was looking at the files. And I said, "Whoa!" And I didn't yell, like everyone had been doing. I said, "We have to start over ." And she looked up, quite surprised, and I said, "You tell me your name, and I'll tell you my name. And I don't want to be your best friend; I don't want to go shopping with you. I just want us to have a relationship because I'm going to be your patient for a while." The tumour had given me double-vision; my eyesight was in danger. And she was so shocked. And I said, "I've worked in healthcare. I know the pressure you're under. But I still think you should take the time right now to have some acknowledgement that there's a person in your chair." And we had a great relationship after that. I think that she was stunned because she was busy and she was under pressure and she was under fire and she was trying to deal with a lot of people, and you see that over and over and over again. It's an overloaded system and people, you know, need time and effort.

But if you're in an institution that is not only treating a disease but treating the people with the disease it's a whole different sensibility. And I have found that in healthcare too; that's the good side, when you go and you feel that even though the outcome might not be what you want. If it's a cancer hospital obviously not everybody's going to come out scot-free, but that everybody cares enough about your experience there to make this hideous

situation as good as possible by acknowledging you as an individual. I think when you seek help from a healthcare provider what you want is an honest assessment of your situation and some proposed solutions, and then most of all you want them to care that it's working or that it's not working, or that you're being treated appropriately or that it's making a difference or "What else can we do?" You don't want to be - have the appointment and then it's over, you know, that the interest in you is completely done. And that's a hard thing. I think people with chronic pain kind of resist a paternalistic/maternalistic care package, but on the other hand a professional can actually make that connection as he would with any patient or she would with any patient, that says "I hear you. What can we do? How can we make this a bit better for you?" And also an honest assessment. I mean, the best clinician I saw said, "Chronic pain - it's an epidemic. We don't yet know how to deal with all of it. Here are the things I recommend for you. Let's try them, and let's in six months see how it worked. And if they don't work, we'll try something else. But I'm here for you anytime you want to pick up a phone and say "This is getting worse", come back." And that was - I thought that was a really great approach. Because it is all experimental; everybody responds differently.

I think there are some very difficult scenarios that play out in healthcare, and as a woman your symptoms are so wide-ranging that they're often dismissed as "it's stress". I've got headaches; I can't sleep; my head is pounding; I'm hot and cold. All those things. And I was told, you know, well, you know, you've got a big job, it's the stress, and then I felt stressed that I wasn't handling my stress well, and I thought, "Oh no, I'm failing at stress-management". But I think that a lot of people are comfortable articulating their needs and are comfortable seeking help. If you're not, it's very difficult because, you know, something like chronic pain can't be seen; you don't have a symptom that is visible, and so, you know, I was worried that I would be kind of a whiny patient - "talking about really and my head really still hurts" - and I didn't want to be a bad patient, and I didn't want to be a whiner, but I couldn't be more specific than that. I mean I started documenting the different headaches I was getting, but I think it is very difficult if you're dealing with stereotype as well as this strange hybrid of symptoms that aren't visible, and aren't immediately curable, if ever. So I think the stereotypes are very, very valid as a concern about getting the right care, and getting heard, and getting believed, so it doesn't look like you're just trying to get off work, or you're just lazy, or you, you know, have no initiative to deal with this, and you don't have a positive attitude. And so much of health is a positive attitude. Well, that's blaming the victim in so many ways because everybody wants to have a positive attitude about how they feel. Everybody wants to feel better. Nobody enjoys wrapped up in a

dark room with ice on your head and feeling horrible, and feeling like you're failing.