

Spinal Cord Injuries
Webcast
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Andrew:

Hello and thanks for joining us once again for Patient Power on healthnet@nmh.org brought to you by Northwestern Memorial Hospital. I am Andrew Schorr, and I'm delighted to host and help produce these series, this series every two weeks. We're doing a new program with a leading Northwestern specialist on an important topic and also featuring patients who've benefited from the care at Northwestern Memorial and have a lot to say about it and inspiring for all of us.

You know, about 10,000 Americans each year experience spinal cord injury, and that's when there's a traumatic event and it damages the cells within the spinal cord or could sever the nerve tracks that relay the signals up and down the spinal cord. Now, of course, it's a very serious injury. Maybe you know someone where that's happened. I certainly do. Could be a car accident. Could be you hear sometimes people during the summertime, as we're doing this program, dive into some murky water, think it's really deep and it isn't, and the next thing you know they are paralyzed or have serious spinal cord injury. Could be a skiing injury, could be football, whatever it is, and it certainly can be life changing. There's a friend of mine where I live where that happened to him when he was biking at lunchtime, and suddenly he found himself--you know, you get air lifted to a hospital. You're rushed into surgery, you don't know whether you'll regain movement or feeling, and hopefully you do. Some people don't.

Well, let's meet a woman from Chicago, an attorney, 34 years old, Erin Kinahan who back in 1993 was a junior at the University of Wisconsin. And if you're a sports fan and you know all your sports you may know that in that year the University of Wisconsin was the Big Ten team that was against one of the Pac Ten teams, UCLA, in the Rose Bowl. So you can imagine after Christmas and before New Year's there were a lot of University of Wisconsin students who were making the trek out to the Rose Bowl in Pasadena to see their team hopefully win. Well, Erin was in the back seat of a car, her roommate was in the back seat too and there were two young men as well. And they had been driving through night, young women drove at night, now was it the next morning, they had had breakfast, they're going on, they're in between the Grand Canyon and Flagstaff, Arizona.

Erin, what happened then?

Erin:

Hi, Andrew, and thank you so much for the invitation to participate in this webcast. I appreciate it.

Andrew:

Sure.

Erin:

But as you had mentioned we had left the Grand Canyon and my roommate and I fell asleep in the back seat because we had been driving throughout the night, and the driver of our car fell asleep while he was driving. And our car flipped end over end. As the car flipped end over end it landed upside down. I was ejected from the car and then the car hit me as I was ejected, so I sustained a T10 spinal cord injury.

Andrew:

Now, T10, as I understand, is sort at the bellybutton level, is that about right?

Erin:

Yes.

Andrew:

And the long-term effect of that has been that you've been paralyzed from that level down, is that correct?

Erin:

That's correct.

Andrew:

So you've been in a wheelchair, and you're a practicing attorney in Chicago and we'll talk about how life has gone on. But I understand you were airlifted to Flagstaff Memorial, I guess it was.

Erin:

Flagstaff Medical Center.

Andrew:

And you were there for three weeks. Your parents rushed down from Chicago, and then eventually you come back and you're helped further at the Rehabilitation Institute of Chicago.

Erin:

Yes, that's true.

Andrew:

And so you had surgery and then a lot of rehab, and eventually you're discharged from the hospital and try to go on with your new life. You finished college, and you're certainly to be congratulated.

Erin:

Thank you.

Andrew:

You worked to help other people with disabilities, I know, with the attorney general's office in Illinois. And then you were encouraged--and we'll hear about that story too in a minute--but you were encouraged to go to law school, which you did, and now you've gone on with a successful career in law.

Erin:

Yes.

Andrew:

Now, that's inspiring in and of itself. But you had a bunch of surgeries along the way too, and I know that often happens. What surgeries did you have, Erin?

Erin:

When I was in Flagstaff I had a posterior fusion where they cut part of my hip bone and they fused T10 so they could stabilize my spinal cord. Posterior meaning they went in through the back. So they did that procedure first to try and lessen the pressure that was blocking my spinal cord. And then about two weeks after I had arrived at the Rehabilitation Institute of Chicago, part of the Northwestern Memorial Hospital, I had an anterior fusion where they went in through the front, again used a portion of my hip bone to fuse T10 from the front and not just from the back as it had happened in the past.

Then a year after that surgery I had another surgery to go in and remove the rods that had been placed in my spinal cord to stabilize me. And then six years later I had a bladder augmentation procedure. I had a neurogenic bladder, and in order to control that better they cut a part of my intestine and they expanded the bladder using a part of the intestine. And then two years after that I had some bowel obstruction surgeries, which is a common complication of the bladder augmentation. Once the intestines are sewed back together scar tissue forms, and that can cause an obstruction, which did happen.

Andrew:

Okay. And hopefully that's all of your surgical journey.

Erin:

Hopefully I'm done.

Andrew:

So now you've gone on. How are you doing now?

Erin:

I'm doing great. I'm very healthy. I have no complaints.

Andrew:

Well, we're going to talk more about that, and of course I'm delighted to hear that. So helping you get to that point is really an expert team.

So let's meet your doctor, who is a physiatrist, a rehabilitation specialist, Dr. David Chen. He is quite an accomplished guy. He's medical director of Spinal Cord Injury Acute Care Center and Rehabilitation at Northwestern Memorial Hospital and the Rehabilitation Institute of Chicago. He's also an associate professor of physical medicine and rehabilitation at Northwestern University's Feinberg School of Medicine.

Dr. Chen, I'm going to share the fact that over your relationship with Erin which has gone on many years you were the gentleman who encouraged her to go to law school, and she's made a whole career of it. So when you hear Erin's story you got to feel good.

Dr. Chen:

Oh, absolutely. And also I want to thank you for the opportunity to join you this evening. And it's individuals like Erin and having known that I've been a part of her recovery and her rehabilitation and her progressing with life is really one of the most rewarding aspects of the work that I and many others in the field of spinal cord medicine, whatever specialty we come from, is really what's most rewarding.

Andrew:

Absolutely. Now, I mentioned sort of the traumatic injuries that we think of often in younger people like Erin, car accidents or sports injuries, but I understand as the population ages you're seeing an increase where it happens in other ways. Tell us about that too.

Dr. Chen:

You're absolutely right Andrew. In the past, when you look back several decades ago at who was injured and was sustaining spinal cord injuries it was predominantly a condition that was affecting younger individuals, individuals just because of the nature of the injury. Motor vehicle crashes, falls, those kind of injuries that take place during outdoor activities and things like that. We still see that today in terms of the numbers of individuals and the types of injuries that cause spinal cord

injuries, but, interestingly, over the last decrease aid we've seen a definite trend, increasing trend in the age of persons who are injured and then an increase in the numbers of individuals in the older age group. And I'm talking in the 40s, 50s and 60s.

Now, part of it is likely due to the aging population. We know that here in the United States the population is getting older. Baby boomers are getting older and therefore having a larger number of individuals in that group now at more risk. And these individuals, interestingly, we tend to see--we still see motor vehicle crashes with them but we're seeing now many more individuals injured as a result of falls.

Andrew:

Right. And there are people, of course, as you get older you may be on some medications, multiple medications. Falls are responsible for lots of problems for older people in particular. So along the way we'll talk, Dr. Chen about prevention, because obviously if there's some things you can head off now.

Erin, you didn't have a seat belt on.

Erin:

That's correct.

Andrew:

And I don't know whether the other three in the car did, but I know that they were not as seriously injured. What do you have to say about seat belts?

Erin:

Wear them. The other girl in the back seat, she did not have her seat belt on either. The two in the front seat did have their seat belts on, but we did not have them on. We just thought we hadn't slept all night. We wanted to get comfortable. But my advice to everyone, please wear your seat belts.

Andrew:

Right. Now related to medications, just a word about that, Dr. Chen, for older people where they could be dizzy or unsteady on their feet, and if you fall down the steps you could have a serious injury in lots of ways and certainly including a spinal cord injury. If somebody has dizziness these are all things to discuss with their physicians to manage that side effect, right?

Dr. Chen:

Absolutely. Injury prevention is certainly something we emphasize in our work at Northwestern Memorial Hospital and RIC. And, you know, it's interesting that when you hear us talk about these types of injuries rarely will you hear us use the term "accident." You know, "accident" implies an unpredictability or a haphazard or

chance of these events occurring. From years of studying these injuries and knowing the type of events that cause these injuries we know that there is predictability to these. We know that there are factors, whether it's because of a motor vehicle crash or whether it's because of a fall or some other type of injury, that there are things that can be done to decrease the risk and the chances of those injuries happening. You and Erin mentioned in terms of motor vehicle crashes wearing seat belts, following speeding laws, all states enforcing drunk driving laws. Those are all injury-prevention efforts that are aimed at preventing injuries like this and other traumatic injuries.

For the older population, even more importantly now as the population is older when individuals see their primary care physicians, whether it be family practitioners or their internist that it's important to discuss medications that they're taking. And if they're experiencing side effects or the problems with it, it's important to discuss those symptoms with their primary care physician so that hopefully events like this can be avoided.

Andrew:

All right. That's our goal. What we're going to do as we continue our program is we're going to discuss and take your questions specifically about spinal cord injury. There's certainly thousands of people listening to this program who have been affected either as a patient or a family member, so we welcome your questions. You can give us a call. Just dial 877-711-5611. Or you can send us an email at nmh@patientpower.info. So just send us a message. We'll be happy to take your question. We've already gotten many and we'll be happy to take those along the way.

We're visiting with Dr. David Chen who's medical director of spinal cord injury and acute care at Northwestern Memorial Hospital and the Rehabilitation Institute of Chicago and his patient, who's been with him a long time and doing great as an attorney in Chicago, Erin Kinahan.

We'll be right back as we continue Patient Power sponsored by Northwestern Memorial Hospital.

Andrew:

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We're talking about spinal cord injury which affects about 10,000 new people in America each year, but certainly there are thousands of people who are living, people with disabilities who you see who fortunately in many cases are going on with pretty full lives. And Erin will tell us more about that as we continue.

Dr. Chen, when we talk about spinal cord injury I see there's sort of a continuum where somebody may have no feeling or ability to move, or they may have something less than a hundred percent. So how does that happen, and maybe help us understand what are the stops along the way.

Dr. Chen:

Well, you're absolutely right, Andrew. The ways in which individuals experience a spinal cord injury can span quite a wide spectrum. I think when most individuals out in public think about an individual who has had a spinal cord injury their probably first impression is an individual who can't move or feel anything below their neck. And that would be an individual who we would call quadriplegic or tetraplegic and is an individual who mostly has had an injury up in the cervical segment of their spinal cord. The spinal cord is a very vital, very important tissue that goes from the brain down the middle of the spinal column. Probably at its longest about a foot and a half in length and maybe at its widest maybe about a half dollar in diameter, but through it run all the vital nerves that transit signals from the brain to and from all the different parts of our body, our fingers, our toes, our feet, our hands, the vital organs within the body. And it's through these signals that carry the messages that tell us to raise your right hand or to raise your right foot or to walk.

And so depending on where the injury takes place within that spinal cord, if it's up in the cervical section, which is in the neck, all the nerves that are below that area are going to be affected and therefore those are the nerves that go to the arms and to the legs. For injuries that are below that level, let's say down in the area of about the level of the abdomen, similar to where Erin's injury took place, on those situations the nerves above that level, so the nerves that go to the arms and hands, have been spared in terms of sensation, in terms of motor function, and therefore they retain their ability to use their arms and hands normally. But below that level, in the legs, those have been affected.

Now, in terms of the extent of the injury, that's oftentimes the unpredictability of it. There are some individuals who even today who have had injuries and if you saw them walking down the street and didn't know they had an injury you might not know that they have had this type of injury and have recovered or improved from it. And there are others who unfortunately haven't experienced significant recovery, and if they lost the ability to use their legs normally then they may require a power-assisted wheelchair or a manual wheelchair for their activity.

Much that have depends on the extent to which the tissues within the cord have been injured or damaged. How much is retained sort of depends on how extensive the nerves within the spinal cord has been injured. Those individuals who have recovered some neurologic function it's usually because some of those nerves though originally injured have been spared and have been able to recover the function on their own. So it really can span quite a wide gap in terms of how individuals present even with very similar injuries at similar levels.

Andrew:

The \$64,000 question I'm sure people ask the surgeons, who they often see first, when somebody has had one of these traumatic events and there's not movement or there's not feeling is, will my son, will my daughter, will my husband, will my wife, will they get some of it back. And obviously with the trauma you have this idea of inflammation and just tremendous trauma, but you think, well, through surgery and through healing some of that can recover. To what extent can the nerves, the tissues maybe that are putting pressure around them, recover so that feeling and movement can come back? And what time window does that typically happen where you can say it's likely to happen now or it's not going to happen at all?

Dr. Chen:

That's a terrific question. That is really the key as to how individuals recover and to the extent they recover. The injury to the spinal cord in the great majority of cases are what we call contusion injuries or bruising injuries. There's a misconception in the public that a person who has had a spinal cord injury has had a complete transection of their spinal cord or a complete cut of their spinal cord. In truth, that really very rarely happens. Only in very small percentage of cases do those occur. And the main reason is because the spinal column or the bone, the vertebral body that surrounds the spinal cord, one of its purposes is to act as a coat of armor in order to protect this vital tissue that carries these signals from the brain to the rest of the body.

But when you look at the nature of how these injuries take place, they're high energy events, motor vehicle crashes, falls from heights. A lot of energy has been transferred to the spinal column, and that energy then, what happens is it causes perhaps a break in the bone, a disruption in the ligaments that hold those bones together, and the bones move on top of each other. And what usually occurs is the spinal cord is bruised. And like any other part of our body, if you've had an ankle sprain, if you've twisted your wrist perhaps by falling on it, there's a natural inflammatory reaction that takes place. The body's reaction is to swell. The same type of event takes place within the spinal cord. And, therefore, because the spinal cord is within that closed space and has nowhere really to expand to, it begins to almost squeeze upon itself, which we believe causes some secondary injury to the spinal cord.

Now, unfortunately, there's really nothing that we can do about the initial injury that takes place. I mean, the ideal would be if you could have prevented the initial event in the first place, but the secondary injury is something that we believe by an individual getting to a trauma center that specializes in spinal cord injury, that way they can begin to focus on trying to minimize the secondary injury that's taking place.

Andrew:

Was that what was going on with Erin's surgery? So she was airlifted. She had compression of the spine by a certain vertebra, right, Erin? And so is that the idea, is try and take the pressure off and prevent that secondary injury?

Dr. Chen:

Yes, that's exactly right. If there is any ongoing pressure or compression on the spinal cord to relieve that in hopes of sparing further damage and sparing some neurologic function, but also going forward, just like, again, if you, let's say, broke your leg or let's say you broke your arm, in order for it to heal properly you want it in a good alignment. You want it properly placed so that further deformities or problems don't take place in the future that may cause additional problems.

So frequently surgery is done after an injury, one, is to decompress the spinal cord and to minimize any further secondary damage to the spinal cord. And two is to realign the spine if there has been some disruption in the alignment of the spine and also to solidify the bone and maintain its integrity for the future.

Andrew:

Okay. We got to get to that \$64,000 and that is, there's one of your new patients and they're saying, Doc, will I get some feeling or movement back? What's the time window when we're looking to see if there's this recovery?

Dr. Chen:

Well, because all injuries are different and the extent which they are different, there really isn't an absolute time window or frame that you want to see things coming back where beyond that you won't. Obviously the earlier you begin to see some improvement or return of neurologic function, whether it be the ability to feel or sensation, or motor function or the ability to move, even if it's a small amount, the better, the greater the prognosis for further recovery. I mentioned before about inflammation and swelling. We know that usually by about four to six weeks after an injury, assuming that any ongoing compression has been relieved, that the inflammation or swelling has usually resolved by that time. So it's not too unusual that individuals who do gain back some neurologic function during that time frame of about four to six weeks begin to notice those changes, those improvements.

So, again, every individual's injury and condition is different, and there is not one absolute time frame that everyone is going to begin to experience return by or that

you necessarily need to see return come back if someone is or is not going to experience further improvement.

Andrew:

Okay. Erin and I were chatting on the phone, Erin, and you recall how you were able to strap yourself up and sort of be in a walking machine that allowed you to stand and exercise that way too. But otherwise you're in a wheelchair, and your hope is that one day there could be a way that could regenerate that spinal tissue and give you back your feeling and movement. And that brings us to what's been controversial, Dr. Chen, and that is the use of stem cells to regrow, I guess it would be, spinal cord tissue. What's your position on that? Where are we with that? Is that the great hope? And it's been politically controversial, do you have any thoughts about that?

Dr. Chen:

I think certainly from the ethical and political issues, if you set those aside, I think that most scientists and researchers believe that as with many other medical conditions that the potential for stem cells as another treatment for neurologic disorders such as including spinal cord injury does have some potential. The work that has been done thus far is still very early on, but there is certainly some promising developments that have taken place in the animal studies and in the basic science in the laboratory. But I think we're still very early on.

Andrew:

Okay. Well, we're going to take a break and we will be back and start with our questions for Dr. Chen. And, Erin, you will be able to chime in and get some specific answers for people. Obviously, we want to know where is treatment now? We talked about the surgical approaches to try to deal with the initial injury and prevent a secondary one, but what do you have in the rehabilitation area to give people back as full a life as possible. We'll talk about that as we continue our discussion of spinal cord injury with Dr. David Chen, who is the director of spinal cord injury acute care and rehabilitation at Northwestern Memorial Hospital and the Rehabilitation Institute of Chicago and a very inspiring patient, Erin Kinahan. It's all coming up as we continue Patient Power Live at nmh.org, and this is brought to you by Northwestern Memorial Hospital. Stay with us.

Welcome back to Patient Power Live on healthnet.nmh.org sponsored by Northwestern Memorial Hospital. Andrew Schorr here, as I'm here every two weeks for you doing a new webcast. In September we're going to focus on prostate cancer. So a guy like me, I think and worry about that. And it's true many older men, most older men will die with prostate cancer, not from it. But there are cases when it's more aggressive when you're younger, so we're going to talk about prostate cancer screening and treatment on Tuesday, September 11, at this time with Dr. William Catalona at Northwestern. And then we're going to come back on

September 25, same time, on a Tuesday and talk specifically about robotic surgery for prostate cancer with Dr. William Wei Lin. So that's all coming up in September right here.

Let's continue our discussion about spinal cord injury. Here's a question for you, Dr. Chen, and it really deals with--Erin, I'm sure what you wonder about too, and that is long-term psychological and physical effects of having the disability of a spinal cord injury. And what Gordon writes in from Chicago he says, "What's the leading cause of death in adults over 40 years of age with spinal cord injury?" He said as a 45-year-old male who has had a T5 SCI, spinal cord injury, since I was 22, I'm very curious what to expect physically and psychologically as I age into my 50s, 60s, and hopefully into my 70s. Or can people with traumatic spinal cord injury live into their 80s and beyond?" So what would you say to Gordon, Dr. Chen?

Dr. Chen:

Oh, I would say to Gordon, absolutely. And here's to a long and healthy life for you. It's because of the many specialties that are involved in the care for persons with spinal cord injury, from urology to internal medicine to, early on, the orthopedic surgeons and the neurosurgeons and all the different specialties that are involved in centers like ourselves that have been focusing on spinal cord injuries, we've learned a great detail over the past two or three decades about persons living with spinal cord injuries and the conditions that they experience and that they sometimes go through as they live longer and longer years with spinal cord injuries.

If you look back 30 years ago the leading cause of mortality in individuals with spinal cord injury was renal failure. So individuals were developing complications of the kidneys as a result of changes to their bladder and their ability to void because of their spinal cord injuries. And because of our learning from those individuals' experiences we now emphasize health prevention in areas like bladder care and preventing renal complications, as one example. And now when you look at individuals who have been injured over the last decade and look at what their leading cause of mortality is, it is similar to those causes of able-bodied general population: heart disease, diabetes, and strokes. So we believe that because we have learned so much about spinal cord injuries and the complications that they experienced so much of our attention now going forward is on health prevention and emphasizing those things.

Andrew:

Okay. We'll get to as many questions as we can. A lot of them relate to this. Now, Erin, you've told me that you live with some pain, correct?

Erin:

I do.

Andrew:

Now, what pain do you feel? It would seem to me, like your legs, you can't move them, you're not feeling anything.

Erin:

Right. I have pain from my level of injury down. It's how I would describe as sometimes a sharp shooting or burning sensation that I have. And the way that Dr. Chen originally explained it to me is that your brain is constantly checking in all parts of your body. And please, Dr. Chen, if I'm incorrect please correct me. But your brain is always checking in on different parts of your body, and because the connection is no longer complete between my legs and my brain the brain checks in with the legs and says, Everything okay down there, and doesn't get anything back, and so then it reads that as pain.

Andrew:

Dr. Chen, was that a good explanation?

Dr. Chen:

Boy, that absolutely was. And it makes me feel good because it tells me that Erin listened to some of the things early on when I was first caring for her.

Andrew:

Let's talk about that. Now, so Erin, early on at the hospital you were taking pain medication that just kind of knocked you out.

Erin:

Yes.

Andrew:

And you're a lawyer, you're in a courtroom, you have high pressure cases and you're right there in the big city, you want to be sharp. So you're coping with that. And so that brings up the question that if somebody's experiencing that pain, and this is sort of what Erik from Chicago writes in about too, he's asking about the common psychological issues that may go with the disability, but maybe the pain that you may be living with over many years. Is there anything that can be predicted there, where you say somebody maybe could live till their 80s and die of the same thing that everybody else does, Dr. Chen, but there may be this load of pain that people are just sort of like carrying, and that's got to be difficult psychologically as well.

Dr. Chen:

Oh, absolutely. You know, the whole area of pain with spinal cord injury is a perplexing, complicated issue because there are so many factors that, whether we're talking about a spinal cord injury or we're talking about in general itself, that can play into it. There are certainly emotional and psychological factors that can

contribute and factor into how individuals experience pain. As Erin eloquently described it, the type of pain that is common in individuals with spinal cord injuries, it's something that we call "dysesthetic pain" or "neuropathic pain" or "nerve pain" is well recognized in these type of conditions and injuries.

And like you said sometimes people say, Well, if a person doesn't have touch and the ability to feel in the area that's been affected how can they possibly have this sensation? Well, the brain and the body is a very complicated organism and frequently signals that we aren't aware of get created in the brain that can sometimes give the brain the sensation of these pain sensations. Some people have asked is it similar to phantom pain that individuals who have amputations sometimes experience, and there is some similarity probably crossover in the type of experiences that they do have.

But in managing this type of condition, it is important we recognize that the use of medications can oftentimes have side effects, and our whole goal in spinal injury care and rehabilitation is to assist the individual to return to as normal and productive a life as possible, whether it be returning to work, whether it be returning to school to their homes and families, and being able to manage these conditions appropriately and without side effects is certainly important.

Andrew:

I'm going to ask a question from the internet in just a second here. First, Mark from Detroit writes in and says, "I'm a 29-year-old C7 quad who's been injured for ten years. Last year I began taking baclofen for muscle spasms and had a horrible reaction to it. I was able to stop taking it this last June but subsequently suffered a manic episode which required hospitalization. Have you had any experience with individuals stopping baclofen and then having psychological issues post use?"

Dr. Chen:

Yes. That is not a too uncommon side effects from abruptly stopping that medication. Baclofen, which is a commonly used medication for spasticity in neurologic disorders such as spinal cord injury, is a medication while effective and generally well tolerated, if it is abruptly discontinued whether by accident or a person losing their medications can sometimes cause that type of psychological reaction.

Andrew:

So what do you do?

Dr. Chen:

So the importance of knowing that information is if a person, let's say, has to discontinue that medication, if they're going in for surgery or having some type of procedure in which they have to discontinue the medication, is to slowly get themselves off it over a three or four period of time.

Andrew:

Okay. Now, do you have a pretty good array of medicines so if you're concerned about one you can switch to another? Do you have a bunch of tools, if you will?

Dr. Chen:

For most of the conditions that are associated with spinal cord injuries, fortunately there are generally options in different medications. If medications are required they're available to manage those conditions. So in spasticity if an individual doesn't tolerate baclofen for whatever reason there are other medications that can also be tried that can also provide the benefit of relieving the spasticity.

Andrew:

Okay. So Craig is joining us. Where are you from, Craig?

Caller:

From Orland Park, Illinois.

Andrew:

Okay. What's your question?

Caller:

It goes back to a little bit of what Dr. Chen was talking about earlier. I was wondering how important is it for there to be an immediate emergency surgery that might relieve that instant compression from the injury. Is there a judgment that's made before surgery occurs or is it something that's just a standard? Many standards will say that they wait three to four days to wait for swelling to go down before they do a surgery. Are there any parameters that a neurosurgeon would have to work in or see the degree of damage to a cord by an MRI possibly to make a judgment on waiting to relieve that pressure?

Andrew:

Okay. And let's get the answer from Dr. Chen.

Dr. Chen:

Craig, that's a very good question, and as you can imagine it's a very complicated issue in terms of timing of surgeries. And because oftentimes with these type of injuries there are many other associated injuries that go along in addition to the spinal cord injury, it sometimes takes some stabilizing before an individual is really in a condition where they can undergo a major procedure like that. So that's certainly one factor that may go into the timing of when is the person capable of being able to go through that type of surgery.

And the second issue is that there aren't absolute parameters or guidelines that necessarily are out there about the timing of the surgery to decompress itself. It is,

because all injuries are different and the extent of what a surgeon may see on an MRI may be different from person to person, that certainly goes into the judgment about the timing of surgery.

Andrew:

Okay. Craig, thank you for that question. We're going to take another break, and when we come back we're going to answer some more questions. We're going to hear more from Erin and Dr. Chen. Remember, you can give us a call just like Craig did. 877-711-5611. 877-711-5611. You can send us an email at nmh@patientpower.info. We're visiting with Dr. David Chen, who is a physiatrist and medical director for spinal cord injury and rehabilitation at Northwestern Memorial Hospital and the Rehabilitation Institute of Chicago, and inspiring patient Erin Kinahan. We'll be right back with more Patient Power sponsored by Northwestern Memorial Hospital.

Now, where can you hear a radio show or webcast that devotes an hour to spinal cord injury and is part of a series where they connect you with leading medical experts every two weeks? Nowhere, except on the Northwestern Memorial website. Thanks to them for sponsoring Patient Power. Okay.

Let's take another call. This is from Rosalie who is calling from the great province of Ontario in Canada. Rosalie, welcome to Patient Power.

Caller:

Hi. My question is I guess more focused on recovery. I'm a C5,6 complete about a year ago in a diving accident, and I'm just wondering what the doctor's view is on recovery treatment places such as Project Walk and I know there's a few others throughout the United States?

Dr. Chen:

Well, I think, Rosalie, that there's certainly places like Project Walk and other programs similar to that are emphasizing an idea called activity-based therapy. And what many of these programs are espousing is that by utilizing the different therapies and modalities that may replicate some of the movements that a person maybe isn't able to do at the present time that perhaps it retrains the nervous system so gain back that function.

There's a lot that we have learned early on from these types of activities that certainly may have promise, but there are also a lot of things that we don't really know. And it is certainly difficult and challenging to recommend or to prescribe those, just like in any other medical condition--a cancer or heart disease--if we're not clear whether there is true benefit from it. So I think we have a lot to certainly still see from these types of programs and I think we have to keep our eyes open and keep an open mind as to their potential benefits and see what happens.

Caller:

Absolutely. As well, the views on recovery as far as spinal cord injury are I guess viewed a lot differently in the United States than in Canada. I have actually been privileged enough to participate in opening a wellness clinic here in Toronto that now has the first Locomats available to the public.

Dr. Chen:

That's terrific.

Caller:

Do you have any comments or any opinions on that technology?

Dr. Chen:

The Locomat?

Caller:

Uh-huh.

Dr. Chen:

That's interesting you should bring that up. We here at in Chicago at Northwestern Memorial Hospital and the Rehab Institute in Chicago, we're the first institution actually in the world to get that system, which is a robotic-assisted body weight support treadmill training. And for the first two years that we had that equipment we felt it was important first to do some clinical studies to try to determine whether there are particular types of injuries and completeness or incompleteness of injuries that would benefit the most from it before we put it into clinical use. And we found in the first two years in some of our early clinical studies that incomplete individuals, so those that have some motor function in their affected part of their bodies, seem to benefit from the use of this modality. And so several years ago we began to introduce this into our clinical setting, I think with some good benefit.

Again, similarly to other newer modalities, I think we still need to study it a little bit more before we can say that it will necessarily benefit everybody before we make it more widely spread available.

Andrew:

Okay. We're going to move on. Rosalie, thanks for calling in from Canada.

And we're delighted to hear about the Rehabilitation Institute of Chicago, of course part of Northwestern Memorial all associated together as a complete resource for you that you were such an innovator there, Dr. Chen.

So, Erin, you spent a lot of time at the Rehabilitation Institute. How do you feel about that place and the quality of care? Now, we've got your doctor on, but I

think you like him. But it takes a team and tremendous support to help people really adjust to a dramatic change in their life and to bring together the different modalities that can give you skills and as much activities of daily living functionality as are available. How do you feel about the treatment that you've received?

Erin:

I feel so blessed to have had the Rehabilitation Institution of Chicago in my backyard. As someone who grew up in the suburbs of Chicago, I just felt really lucky that I lived so close to it and received outstanding care while I was there from the physicians, from all the healthcare providers that I encountered. When I was there--I was there for a little less than three months. And as a paraplegic nowadays, insurance certainly won't let you stay there that long, and I was trying to soak up every single minute of therapy I could get so that I could feel as prepared as I did feel once I was discharged. I am so grateful for the opportunity to have been there.

Andrew:

Now, at some point you go on out in your life. You work with people with disabilities on behalf of the people of Illinois working with the state attorney general, and then you went on to law school. Now, you learn to be assertive as a lawyer, but I think you have to learn to be assertive as someone with a disability. What counsel would you give to someone where they're getting past the trauma but this is all new to them, so that they can, whether it's with family, friends or somebody who's ahead of them in the elevator and they need a little more space, how do you carry on so that you feel you're living as full a life and getting the respect you need, too?

Erin:

One of the first lessons that I was taught at the Rehabilitation Institute of Chicago is that I need to be able to direct my own care, meaning as much as other people may think they know what I need I'm really the only one who knows exactly what I need and the best and the most efficient way to get what I need. So that taught me that I need to tell people, Hey, could you hold that door for me, please, or whatever I need help doing. You can't be shy about it, because people don't know. 99 percent of the time people aren't used to dealing with someone in a wheelchair or not, they're not really sure what they need. So it's really, really important to be vocal and explain what you need.

And on the flip side it's really important for family members, friends, loved ones to really listen to the person with the disability and listen to what they need. Again, sometimes they think--"they" meaning the person without the disability, knows what's best for the person with the disability, but it's really important to really listen to what they say and what they need.

Andrew:

I got one other question I want to ask you. Certainly we talked about people who are older who may have spinal cord injury as the population ages and as Dr. Chen pointed out, and they may or may not be in a relationship, but many of the people who are traditionally affected are younger and may not be married. You certainly weren't as a college student, and now you're a single woman in Chicago with a career. How do you handle relationships, and sort of sometimes you'll meet somebody new and there's things that aren't spoken. How do you just get things on the table so that you can dispel any mysteries or misconceptions and just go on and enjoy being with someone?

Erin:

A lot of times it's easy to just explain what happened. A lot of people want to know my story. Have I always been in a wheelchair? How did this happen? And the sooner those issues are confronted, the easier the remainder of the conversation or perhaps even the relationship will be. Because your fronting issues that everyone is always thinking about. So the sooner you address them and get them out on the table the better, in my opinion.

Andrew:

Okay. Dr. Chen, so I know that there hasn't been a breakthrough in the treatment of spinal cord injuries. There's been refinements in surgeries and learning about when to do surgery, when to do follow-up surgery. Erin talked about bladder augmentation to help people and how that can be done. Certainly aware of what complications can be as she faced that. Certain machine and drugs to help as well. How hopeful are you that we can continue to move things forward and improve and the kind of work you're doing at the Rehabilitation Institute of Chicago?

Dr. Chen:

Oh, I'm very optimistic. I think that when you look at the advancements that have been made both in the care and in the focus on treatment for spinal cord injury, we're years ahead of where we were several decades ago. In part some of that has been due to injuries to prominent individuals, celebrities that have allowed the focus to be on this medical condition. But because of that I think there's certainly much more greater awareness of spinal cord injuries and the potential for improving the care that we can provide with those individuals. So I'm optimistic.

Andrew:

Good for you. By the way, for those who are listening who may not be a patient of Dr. Chen, not have a connection with Northwestern Memorial or the Rehabilitation Institute of Chicago, if you want to check in with them you just go to website where you're probably listening, nmh.org, and there are ways to request an appointment on line. And certainly there are clinical studies and ongoing research, and as you live as a person with a disability you may want to check in with a leading academic

medical center like Northwestern Memorial to see is that something you want to participate in and could this give you an advantage or better quality of life as you move forward. And so we all work together, Dr. Chen?

Dr. Chen:

Absolutely.

Andrew:

To see can we make life better. Well, I want to give the final word as we wrap up today--we're going a little bit over our hour, but it's such an important topic--to Erin Kinahan. Erin, so this happened many years ago. You've had a long time to sort of make peace with it. There can be a lot of anger, a lot of frustration, a lot of trauma and even ongoing pain. You've started a career, and you're well into it now. What would you say to people so that they can just go on with their life? And as part of that tell us what your outlook for the future is.

Erin:

To people who are newly injured my advice to them would be to take one day at a time. I think that sometimes if you try to tackle the big picture it gets a little overwhelming, but if you break it down and take it one day at a time and celebrate each and every accomplishment that occurs, I think that helps makes the transition into the change of your life a lot easier.

And I just decided to dwell on what I have as opposed to dwelling on what I don't have. I'm blessed that I still have full function of my arms and my hands, and I didn't suffer any head trauma and I still have all of my intelligence, so it's a lot easier to focus on what you have than what you don't have.

As far as the future is concerned, I'm hopeful. I'm trying really hard to stay in good shape and take care of my body so that when the time comes where there might be an opportunity to regain any part of anything that I've lost I'm ready for it, so I'm anxiously awaiting that day.

Andrew:

So folks when you see that beautiful woman rolling along by the water off Lake Shore Drive, that's you, Erin, right?

Erin:

Maybe.

Andrew:

Maybe so. Maybe so. Well, I want to thank both of you for being with us today. Really, you've helped us Erin. You've inspired us and we wish you well.

Erin:

Thank you.

Andrew:

And I'm going to go along with you some day on that walk or ride along the water there. And don't want to meet you in the courtroom. I know you must be ferocious. And, Dr. Chen, I know, as we said at the beginning, it's thrilling that we heard that she's doing so well.

Dr. Chen:

Thank you, Andrew.

Andrew:

Thank you, sir.

Erin:

Thank you.

Andrew:

Thank you. We've been visiting with Erin Kinahan, inspiring spinal cord injured patient who's going to go on for a long life, and Dr. David Chen, medical director of spinal cord injury acute care and rehabilitation, Northwestern Memorial Hospital and the Rehabilitation Institute of Chicago. As always, knowledge can be the best medicine of all. Join us again in two weeks as we talk about prostate cancer. Have a great evening. Andrew Schorr for Northwestern Memorial Hospital and Patient Power signing off. Take care.

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