

Transitioning from hospital to home

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[00:00:05] **Janet Dean:** Hi there, I'm Janet Dean and I am a pediatric nurse practitioner at Kennedy Krieger Institute. And today, the topic that I'm going to be talking about is transition from hospital to home. And what I know about this subject, I learned from my patients and what they've taught me and when things don't go well, I've learned that from patients. And the first night I was here, I sat at dinner with my friend here, Paul Garrett, and he's an adult and I'm a pediatric person and he's had personal experience. So, I thought we'll team up and do this. He's done a lot of stuff in Canada. And so, I'll let Paul tell you a little bit about himself here.

[00:00:50] **Paul Garrett:** Absolutely. Thank you so much. This is really a pleasure and an honor to be here. My name is Paul Garrett. I'm from London, Ontario. And even though that's not far from - no?

[00:01:04] **Audience member 1:** Mic switch. Sorry, sir.

[00:01:07] **Paul Garrett:** How's that? There you go.

[00:01:08] **Janet Dean:** Yeah.

[00:01:09] **Paul Garrett:** I'm here now. Yeah. My name is Paul Garrett. I'm from London, Ontario. That's about two hours from Toronto. About, well, across the water, about four hours from Rochester. Cleveland's about three and a half. Anyway, I'm in that area of the lakes and it's really be a pleasure to be here. About three and a half years ago, I was just getting ready to go off to work and it was on a Saturday morning. And I suddenly got numbness in my legs, and it crept up around my buttocks and down the other leg. And I tried to get up the stairs to talk to my wife about what might be happening. I got to the bedroom and the bottom line is about 30 minutes after that numbness, I was paralyzed from the waist down with something called transverse myelitis where the myelin or the covering at the base of your spine with the spinal cord and the nerves are - gets a lesion on it, comes adrift and it opens at ross so the nerves to shut down to protect themselves.

[00:02:12] So, for the past three and a half years, it's been a journey and it's been a journey and a learning experience, and I've met so many wonderful people. And I'm here now where a place I never would have been if this hadn't happened. So, there are, I guess bonuses to this. And so, we're still fighting the transverse. We started with acute care, which got me on the line to knowing what I had. And then we went into - we went

into rehab hospital where we began our journey of learning to be who you're about to be again in your life. The new Paul if you will. So, we've been working on that very closely for the past few years and I'm now very involved with the process with the Lawson Institute and Parkwood Institute as well as the hospital care clinic up there. And we're trying to help people transition back into the community when they've been hit with such a sudden shock to their system. So, that's what we're here doing today and it's really a pleasure. Thanks for asking me.

[00:03:12] **Janet Dean:** Alrighty. Oops, I did it. I knew I was going to do it. Okay. So, as Paul said, you know, these neuroimmune conditions just come out of the blue and they can - they have anywhere from a mild to severe effect on individual's physical functioning and health. And they also have a profound effect on psychological systems in the individual and the entire family. And so, you know, sometimes for people may want after their diagnosis to just go home. But it's really, really important that people go to an inpatient rehab program, because in order for people to be able to do intensive rehab, they really need to have a medical team behind them that can help with all the medical issues. And a psychosocial team that can help with all the psychosocial support to enable people to be able to do therapy.

[00:04:18] So, the inpatient rehab team is made up of a bunch of folks that I showed on the first slide and the really the goals of inpatient rehab, the short-term goals are, you know, for children, especially short-term goals need to be developmentally appropriate. And they're focused on functional independence. And in the short-term, people may need compensatory devices to help with regaining function. And the long-term, we're working on recovery of function and mitigation of long-term consequences. And the rehab team provides psychosocial support and education to the patient, the caregiver, and the family. And also works on medical stability and mitigation of symptoms with the ultimate goal of transitioning back into the home and community.

[00:05:12] So, transition to home involves discharge planning and preparation needs to begin shortly after admission to rehab. And people that had these conditions at that point likely aren't even going to know what questions to ask about discharge planning. So, many facilities have a discharge planner that's either a nurse, case manager, or often a social worker that are going to help guide this process home. And don't be discouraged if your function at discharge isn't what you would like to see it to be, because recovery as long, following these conditions. So, you know, the inpatient rehab is only the start of your recovery and rehabilitation.

[00:06:00] So, topics to consider for discharge planning or transition to home where you're going to need to think about ongoing medical care, ongoing rehabilitation, psychosocial support, mental health, cognitive support, including coping and adjusting. And again, parents, spouse, family supervision or assistance needed at home, funding resources, home modifications and equipment that's needed, transportation and then plan to return to daily activities and previous roles such as school or work. And the first topics that aren't bolded, there's other presentations that are going to cover them. So, Paul and I are going to look at mostly more of the practical aspects of discharge planning in the topics that are bolded.

[00:06:50] So, ongoing medical care, we're just - I'm just going to throw some slides so that people who are watching from home or later can see build your medical team, identify pharmacies, and get medications, and order any nursing supplies. Ongoing, you're going to be looking for PT and OT and speech if needed, you know, locating community in your therapy, looking at equipment that you're going to need for home to be able to be as independent as possible in your functioning, psychosocial support, and mental health. You know the members of the team, social work, rehab, psychology, coping and adjustment, role disruption. You need to - if you have cognitive dysfunction, you're going to need to be learning some strategies for that evaluation of mood, medications, family support and peer support.

[00:07:39] So, first assistance that may be needed at home. So, number one is you know, many people need assistance at least initially from their family. And if you don't have family then there's going to have to be other types of care that can be provided. But even if you have skilled nursing care or personal care assistance, your family is going to wind up being the backup, because there's going to be days when people don't show up and things like that. And then family care can include just supervision, but because of age for young children or maybe for older adults or if there's cognitive issues and then ultimately for anybody that can go into independent living is really important. And there are in the United States, there are centers for independent living in every state that are designed and operated by individuals living with disability, to provide resources for independent living.

[00:08:43] Home modifications are another thing. Ramps for getting in and out of the house are probably the most important thing that needs to be done if you're having difficulty with mobility. You need to have two exits and evacuation plan, and then emergency preparedness plans. You know, Hurricane Ian just came up the East Coast. If you have a multistory home, you know, the easiest thing to do is a first story set up, stair glides or another option, bathroom modifications. And if you can't have access to the bathroom, then you could use a bedside commode. And if you don't have access to showers, you can do a sponge bath or a bed bath. And then widening doorways for wheelchair or walker access. And keep in mind that you know what you look like when you come home is not going to be what you're going to look like necessarily a year for now. So, you have to take that kind of into consideration.

[00:09:44] Transportation, in the States, Medicaid provides transportation for emergency transport or medical appointments. Learning how to use public transportation can be important. Private vehicles, in order to return to driving, you're going to need evaluation and training for adapted equipment if needed. Vocational rehab programs may help with funding. If you're a child, you want to - you're going to need access to school busses. So, you want to be sure that the wheelchair that children ultimately get can be tied down in a school bus. So, I'm going to let Paul talk about these. So, tell me about your transition to home and what kind of care you needed to begin with and maybe what you need now.

[00:10:31] **Paul Garrett:** Sure, you know, I was very fortunate as we went through the whole transition that started really day one in the hospital when we got to Parkwood when my nurse that was my lead nurse said to me, "Here's a binder. It will start it off with that and it has certain aspects of your life and where you're going to be going through this transition through the hospital through OT and PT." And there were pages with just stubs of things yet to be filled on to. So, she said, "That will fill up with things to do with nutrition, things to do with physical exercise, things to do with your doctors, things to do with your specialists. And that's all going to fill up. This binder will become very thick with information."

[00:11:15] So, that was part of the transition to home. So, what I worked very hard in there was to make myself as strong as possible to make the transition back to our home. We had tremendous support in there. As I said, started from day one. Folks, obviously, I went to the PT sessions, the OT sessions. I learned, I understood that you have to accept that the situation you had, and these folks are professionals and they're going to show you how to live your life again.

[00:11:43] So, we did that. We got to about a couple of weeks out and then we had a meeting with all of us together. That would be my practitioners, my OT, my PT, my doctors, my nurses, everybody sat there and said, "Well, where are you right now? How do you feel about this?" And I was pretty confident to be honest with you, because I never let this bother me. I always thought you know; we'll just fix this and move on another day. But the practical aspect to it was I had to get to the home, and I had to get back to my life. So, they

came out to our house, and they looked over, the OT and the PT, Charlie and forget it, brain fog. And then they looked over the house and they determined what we needed and what we needed for me to get back home.

[00:12:31] Now, fortunately, I'd recover some walking by that stage, not strongly, but I could use a walker and I could sort of make it upstairs which made my life easier. When we first came to the house, I went with them, the first time I'd been home since the incident and this was like three months later when I, you know, my dog almost tripped me as soon as I got in the door and that kind of thing. But there was three months later, and Brenda and Charlie had been working so hard to determine what we needed in the house to make it right. Brenda's my wife and this whole incident that happened, she had to take charge of all these things. I really didn't have any, wouldn't say saying it of course, but I didn't have any ability to do anything about it. So, she worked very closely with the transition team and very, closely with OT and PT, and she made sure with what they said I needed new rails going upstairs. I needed the rails because we come in the garage rather than the front, because there was no rail there, it was easier, and some modifications to the bathroom. Well, she had to organize all that. So, luckily, we didn't have a lot to do, but we had a considerable amount to do, and I was still very weak at this stage. So, she organized everything, she got the rails up, she got everything up, she got it ready for me to come in. Practicality was, I was able to get home, I could sit in the car, I could get back to the house and I could walk into the house. And then with walkers I would get into the living room, etcetera.

[00:14:00] Once there, of course, I was doing most things myself, but there were certain things I couldn't do. Brenda took overlooking after all my medications. She took over making sure everything was in place. You know, and the food was in the house. I mean all these incidentals that aren't incidentals that had to be looked after by someone in your world that can help you. I worry about the folks out there that don't have people in the world, and we're sort of looking at that too. But I was very fortunate.

[00:14:26] I was also very fortunate that my injury wasn't devastating to the fact that I needed major changes to my home or major changes to my world. We had to leave the house, because getting up and down the stairs was over a long period was really not practical. So, we moved into a condo and we're all on one level now, but we still needed rails put into the bathroom and certain things done in the kitchen so that I can get around. If I'm in the kitchen, I can walk around and cook and so on. So, yeah there was a lot to do.

[00:14:58] And then the practicality also is I had to drive again. So, we had to figure out how to get me on the road, and there were options for that with Parkwood. They had a thing where they would teach you how to drive with hand controls which I've gotten to master quite nicely now. But that took several weeks to get that working. And so, gradually with all the support and in the meantime, I was going back to outpatient physical therapy at the hospital. And at this point, it was all working together, and my life was becoming stronger and more direct. I was able because of the support and people I knew I could count on and talk to, that I was able to move on, start a new career, get involved with the SRNA which has been a wonderful thing and some other groups up in Canada that I deal with as well. So, all that was about people helping me transition from May 25th to today here in Los Angeles.

[00:16:04] **Janet Dean:** Excellent. So, some other things that are important in transition is you know, funding resources. So, commercial insurance is one option that people know of or your you know, single payer health insurance program.

[00:16:21] **Paul Garrett:** Absolutely yeah.

[00:16:23] **Janet Dean:** There's public health insurance here in the United States. Public insurance or health care exchanges through the Obamacare. Social security, disability insurance is based on work history and

can be applied for. SSI and Medicaid are based more on need. There's Medicaid disability, so for people that are 65 years and older, may be eligible for Medicaid disability. And then severe disability greater than two years of age, people may also be eligible for Medicare disability. There are some waiver programs especially for children that are ventilator dependent. There are - many states have waiver programs that allow them to transition back to home. There are also waiver programs, some for people with spinal cord injury or with brain injury that can be looked into, as well as different community programs that your social worker and folks at the hospital can help you with some access.

[00:17:29] So, return to school is a big transition also, you know, for, I'm thinking mostly of children, but we have lots of students that are in college that return to school. And getting back to school for kids and you know, teens can be normalizing. It gets you back to a good routine. Age-appropriate development is developmental activities are provided through peer interaction in the educational and social setting. We had to assist the school professionals and the family to develop IEPs or 504 plans. Modification of school environment, you know, it may be needing a modification for the length of the day, assistance that the child will need at school, preparation of the school nurses and the educators on, you know, if kids need special equipment and you know, our kids on ventilators all go back to school and they need nursing care and help with that, and any adaptive equipment and assistive technology that would be helpful to access their educational program. And these could be like mobile arm support, standers. Some of our kids with AFM needs cervical collars.

[00:18:43] And then there's preparation of their peers. Our child life department helps with, you know, helping the children develop a social story so that they can - they know what to tell kids about what you know, what their disability is and that kind of thing, and so that they can practice that and feel comfortable with that. And then often professionals may go into the classroom and give age-appropriate presentations to the class. And many of these things are also needed for return to employment.

[00:19:16] And return to employment, each state has a vocational rehab program of some type that vary from state to state but they do provide funding for return to work or return to college or school. There is family medical leave act available for individuals and caregivers that have to miss work so that they can still receive payment or maintain their jobs. And then the ADA, the American with Disabilities Act, you know, requires that employers provide reasonable accommodations to qualified applicants. And that means any modifications or adjustment to the job or a work environment that enables an applicant or an employee with a disability to participate in their essential job functions. So, Paul, tell me about your transition back to employment, work.

[00:20:17] **Paul Garrett:** Oh, yeah. You know I had to do something. I wasn't ready to retire and financially as well as mentally. And I've been in contracting business for years and years. And so, I was used to dealing with loans and things for people's homes. So, I got - I went back to college and I got my certificate to become a mortgage advisor. So, now I'm in the financing industry for helping people fulfill their dreams of buying their house basically. So, but you know, I was able to do that, I did it online. I was shocked at the fact I got a decent grade on, because things don't always you know respond as well at this stage. Yeah. So, I've done that, and I've been doing that plus this for about the past two and a half years now.

[00:21:02] Yeah, and I've met a lot of people in the community. I do a lot because of this. I do a lot of work with the Kiwanis, where I'm the Youth Services Committee Chairman and we raise money and give it to children basically around the world. And help them getting their education and giving them a kick start. So, everything you do and everything that happens in your life can be for a reason. And this truly was because I was not doing as much, I was not as active in the world, in the real world as I am now before this. It was a day-to-day situation where you were living your life, and I'd probably still been doing the same thing and that was fine. But this is exciting. It's different and it's just, yeah, the transition, well, it has been one. But in other

ways, I think it's been something that was meant to be for me in some ways. I, trying to tolerate the pain and things every day. That's tricky to do. But we manage and that's the - and that is about the transition too. You have to, the new world, the new you basically and how you have to deal with that.

[00:22:14] **Janet Dean:** Tell me something about leisure activities.

[00:22:17] **Paul Garrett:** Leisure activities, well, jeez. You know I run - no, hang on. I used to. I used to be a pilot. I flew a lot, but I can't do that now because of the medications basically. Yeah, they won't give you a license for that. I go to the gym still and trying to work out an upper body development situation. We like to travel, my wife and I, we like to visit our friends nearby. We're starting to open up. This is the biggest travel I've done so far coming here and I did this on my own, and with some kickback from my girl about that. But other things that we're doing, we worked together in the house a lot. So, basically, we enjoy each other's company, and we did, we go out and we visit markets, and we just enjoy life differently. It's commerce, it's easier. Yeah.

[00:23:07] **Janet Dean:** But I was, when we were talking at dinner the other night while you were a pilot and you don't fly independently anymore, you have support from good friends that-

[00:23:17] **Paul Garrett:** Hang on. You're right about that. Absolutely. I've got a - I got a nephew who's a pilot and he will have no problem taking me up and actually letting me sit in the left-hand seat and pretend that there's like a wheel that's like in a kid's car thing. And the folks that I used to, my FBO, the flight field-based operations I used to fly out of, well, I can just give a call and reserve a plane and he'll set me up with a pilot and he doesn't charge me for it. And/or he'll come up himself and he's a great guy, and he'll just be my feet basically and I can do the rest. So, yeah, that's a lot of support.

[00:23:53] **Janet Dean:** So, it's good, you know, it's important to have support from family and friends and stuff like that. So, I was going to just say, and this is the last slide I have, you know, what patients have told me is that you know that first year can be pretty tough at least the first year. People are happy to be home and begin the process of figuring out their new normal, maintaining hope for ongoing improvement and function. But then on the other hand, like parents of kids with disabilities always tell me that they're just always afraid they're not doing enough for their child with a disability. And I'm sure that well, I'll have Paul talk about this, the experience he's had.

[00:24:36] And then there's, you know, some of the challenges especially with like children that are on ventilators and have a lot of equipment and supplies is, you know, it's the coordination of care. Parents tell me that, "If all I had to do was you know, help take care of my child, you know, it wouldn't be, it would be okay." But it's all the coordination of care that they have to do. They have to schedule follow-up appointments and order equipment and supplies and make sure they come every month and you have to deal with all the insurance of issues, finding and maintaining good therapy or good care at home.

[00:25:15] And often people have to travel for this. And I forgot to say that about rehab, inpatient rehab. There may not be inpatient rehab near where you are. So, families often have to travel to some place that has expertise for inpatient rehab, which can be very stressful. And then peer support is really important. We heard that yesterday from all the folks that told their stories. But that there are positives. And you know, parents tell me that they're just always amazed at how resilient their children are. And I'm sure Paul's wife would probably say the same thing that she is just, you know, truly amazed at how resilient Paul has been through this. So, Paul, you want to tell us about kind of, you know, things that you think are important for?

[00:26:03] **Paul Garrett:** Oh, I tell you, stay close, keep open mind. You got to slow down your life and just, and to see it differently and appreciate those that are around you, appreciate those that were around you, but you

didn't notice, and you suddenly go, "Oh, I should have noticed them. They were wonderful people." And just be observant of the world. Enjoy, try to make a difference. Just try to do more than you've ever done before.

[00:26:34] And what I find by doing that is it helps me in my recovery. All these things are selfish almost. But by staying this busy and doing things, it helps me generate more positive recovery for myself. I get energy from others. I get energy from my family. I've got three beautiful kids and nine grandchildren, and I sometimes I don't know where my legs are when my grandchildren are around. So, I says, "If I lose my legs, just tell me where they are. Okay? Because I don't know where my feet are." And they go, "Grandpa, your feet's right there." And I go, "Oh, there it is, thank you so much."

[00:27:10] **Janet Dean:** I wanted to ask you one more question about, I know you are telling me that your wife has been very involved in caregiver.

[00:27:17] **Paul Garrett:** Absolutely, yeah.

[00:27:19] **Janet Dean:** So, you know, it's a big change for his wife. And so, she's been very involved in helping other caregivers to negotiate this.

[00:27:27] **Paul Garrett:** Yeah. So, thank you for asking that. That's quite true. Brenda's been involved because of this. We sort of got involved together when I was first working with Parkwood Institute. I was asked to come on to a committee that was developing a program for inpatients, where you could find out things within the hospital and in the community, where to go and get a, you know, your prescriptions filled, where to go and get a taxi, where to go and do anything. So, they were developing that program and they brought me in. And I said to them, "Jeez, would you like to get a caregiver input to this?" And they said, "Yeah sure." I said, "Well, I'll bring my - I'll bring Brenda along." And that was about two years ago or so, two and a half years probably forward now and she got - she took the bit and she just got involved in it.

[00:28:12] And now besides what I'm doing with it, she is with the patient caregiver program and it's a group that is actually developing with Parkwood Institute and with Lawson Institute and Parkwood main. They're developing programs to assist people in getting back to their life when they come out of rehab, when they come out of any situation to try and find those people and save them that they sort of get away from the system. So, yes, she's become very involved in that. And when we talk about this, she's more proficient than I am, because she's just - she dove in and she's enjoying it. She's making a difference.

[00:28:50] **Janet Dean:** Excellent. So, I think we're at the end of our time. And so, we will open up for questions if anybody has questions.

[00:29:07] **Audience member 2:** I guess for me, my son's been at Seattle Children's for two years. And part of the challenge is medically complex issues but then also the shortage of home nursing. I'm a planner type personality and I keep asking over and over, "What can we do to start his rehabilitation now and have that be that same team that transitions when we bring him home?" And they can't seem to really guide me with that because they're not sure either. So, I guess I just would like to know what I should ask or what I should know, where I should see, or where I should start researching, because-

[00:29:39] **Janet Dean:** Yeah. And is your child still like in an intensive care unit setting?

[00:29:42] **Audience member 2:** He's a full support. So, he is on the pulmonary floor because he is on the vent at nighttime. He is on HME during the day. He's currently immobile and non-communicative. He does or did have optic neuritis but he's tracking now. So, we're not sure, because he can't tell us. We're not sure to what's-

[00:30:01] **Janet Dean:** And is there a rehab team at the hospital?

[00:30:05] **Audience member 2:** Not for his inpatient status. There is a rehab unit there. But that's like when he gets to the outpatient stage and then he can become an inpatient rehab but he's still immobile still that he can't achieve the goals. And, but it's like well, how do you expect him to achieve the goals if he's not getting the attention he needs, because he's bed bound. I mean, we cannot find a common ground here and that's the challenge I'm running into.

[00:30:33] **Janet Dean:** And that can be a conundrum.

[00:30:37] **Audience member 2:** Yeah.

[00:30:38] **Janet Dean:** And it may be that you need to find a program that can work with children with all the conditions that your child has. So-

[00:30:49] **Audience member 2:** Okay.

[00:30:41] **Janet Dean:** Being a low responsiveness level as well as, you know, spinal cord injury, immobile. And so, there are programs out there, but you may need to travel. So, we can talk.

[00:31:03] **Audience member 2:** Okay. Thank you.

[00:31:12] **Audience member 3:** Just a quick point, you know, that - Hi. Yeah, that whole transitioning to home. It was really, I mean the PT and the OT that I got in the rehab hospital was fantastic. And, but at some point, they say, "Hey, you're good enough to go," and want to boot you out. And they talked about home care nurses and things like that. And we're on a single-story house, but there is a little ledge to get into the door and all that kind of stuff and they basically said, "Hey, he's coming home like tomorrow or the next day. And you know, you're going to have your house ready." And there's nobody to help. Luckily, I had a, you know, a buddy I worked with that built me some ramps and/or for her, and for me, for the ramps and bars and all the grab bars and all that stuff, but we really felt like we were thrown to the wolves and she was like, you know, panicking, like, "Hey, how am I supposed to get him in the door? You know, he weighs a lot more than I do and I can't, you know, horse him around and stuff like that." So, anyway, there's definitely some room for improvement, but it's all worked out for us, and you know, I get around a lot better now and all that kind of stuff. So, thanks.

[00:32:41] **Paul Garrett:** You know, when you first get home, it's a dark place, because your house is the same, but it's not the same anymore, right? And you do feel like you're in the wilderness a little bit. And when I reflect on that, I remember that I remember looking out the window and I'm going, "Oh, my God, that is the same window, but it doesn't look the same from where I am." So yeah, it was tough to - once you're out, you don't, you can't just push a button and get help, right? Yeah, I know.

[00:33:03] **Audience member 3:** And this whole wheelchair that I got couldn't go through the door, so.

[00:33:07] **Paul Garrett:** Right. Yeah. Yeah. So, yeah. So, things you weren't prepared for, I got you. Yeah.

[00:33:15] **Janet Dean:** I get it.

[00:33:18] **Audience member 4:** All right. Oh, another question coming in.

[00:33:28] **Audience member 2:** Piggybacking on both of you, one thing I've noticed with myself is I haven't done a whole lot of changes with our house, because I'm worried as whether or not that will be traumatic for my son. So, I'm kind of stuck in that conundrum as well because it's like, okay, obviously we're going to need to know what those make changes, but I still don't know what that is. But at the same time, I don't want to change too much, because I don't want Nico to come home two years later and see everything completely different. Sorry, I'm struggling with that.

[00:34:01] **Paul Garrett:** Yeah. You're in that position right now where you are, right? Because you don't exactly know what you're going to need, and I get that. So, you just kind of have to go along with it and gradually figure out what you need to do right now. If they, and then you can figure out what you need to do to get things started and then work through it. You just got to sort of sit from outside and you got to look after you, right? Because it can be terribly stressful. So, ask for help. Get people to assist you. It's very important to do that.