

# Transitioning From Hospital to Home

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[00:00:00] **GG deFiebre:** Thank you, Dr. L.A. Campbell, for joining us again today for the session, "Transitioning from Hospital to Home." Dr. Campbell is Rehab Program Coordinator for the Barrow MS Comprehensive Care Center and the Ashlyn Dyer Aquatic Center, so thank you so much for joining us again. We really appreciate it.

[00:00:22] **Dr. L.A. Campbell:** Thank you, my pleasure. A little extra about me is that I'm a Doctor of Physical Therapy by background, and I'm also a Multiple Sclerosis Certified Specialist through the Consortium of MS Centers. And I have no disclosures to make today. So, transitioning from hospital to home is a very large topic. There are many, many things that an individual can have questions about or things that you need to consider when being newly diagnosed with a rare neurological disorder or demyelinating disease, and then having to move from the safe environment of a hospital back into your home. So, I decided to break this into four core or four essential areas to consider when returning home just to give you some ideas on things to prepare for, and those four areas are the physical environment, the physical experience, entering the medical system and the emotional experience.

[00:01:31] So when speaking about the physical environment and preparing to return home, a lot of your preparation for this process is going to be determined by your inpatient stay. If you're coming from an inpatient rehab facility, your inpatient team of therapists, physicians, social workers, discharge planners, they'll all be able to help you with a lot of these bits and pieces of information and things to consider. If you're going home from an acute care hospital, then these are some of the things you may have to do on your own. A lot of times, you can get your friends and family to help you with this process. Some of the things to consider is that you might be going home with special equipment. You might go home in a manual or a power wheelchair. You might have a hospital bed. You might have a walking aid that you didn't have before such as a walker or a cane. You may also have shower or tub equipment that's very specialized. So because of having special equipment that's now got to go into your home, it's really important to look at your home and to create appropriate kinds of paths around your furniture so that they're wide enough for you to maneuver. Preparing for transitioning between floor types such as going from carpet to smooth floors, and vice versa, in a hospital you're used to just smooth floors, but going home with carpet can be a little bit of a different experience. There may be doorway challenges if your doors aren't wide enough, or you may have to problem-

solve how you're going to maneuver equipment in and out of bedrooms or things like that, or you may have to just determine a different location in your home to place your hospital bed or your power wheelchair. For showers, bathing, and toileting, making sure that you have your equipment set up so that it's easy to use. If you need to have grab bars installed and things like that, it's a good time to do that so that it will make your transition as easy as possible. And then another thing to consider is understanding what it will mean to navigate around pets and small children. This can be a little bit of a different thought process than just walking around your home as you might have done in the past. When looking at the physical experience, these are a lot of the common things that many of you probably already know or have experienced, and this can be symptoms such as really profound fatigue, muscle weakness, paresis, even paralysis for some people, poor coordination, challenges with your vision, balance problems, having to deal with spasticity or muscle spasms that are not very comfortable and then this idea of changing how you get around.

[00:04:34] You have to use a different approach to how you move around, and things may not feel as smooth and as easy to do as they did before. So just understand there are some potential solutions, and one of the most important things that I talk to all of my patients about is pacing yourself, learning to pace yourself. Schedule rest periods. Schedule breaks during your day just like you schedule, you have your medicine schedule because it's really important to allow yourself to recuperate gently as you go home and face new stressors and new challenges and new frustrations. If you've been given a home exercise program from your inpatient therapist, make sure that you consistently continue to do that until you start with your outpatient team. It's important to keep those muscles moving and activating and to keep your sensory system responding to things in the environment and to keep your stamina going.

[00:05:39] If vision is an issue for you, there are programs that you can, and apps you can download onto your phones and tablets that are magnifiers or other technology that can expand and adapt written text so that you're better-able to see as your eyes are beginning to adjust through optic neuritis. Go slow, and don't fight your body. It's a very important thing to consider. One thing with spasticity is that, the more you fight it, the more it fights back, so make sure that you go slow. You're learning new things. It's a new learning curve for you right now, so give yourself some time. Be patient with yourself and allow yourself to adapt and learn easily and smoothly.

[00:06:33] A big issue is that once you leave the hospital, you're now going to have to enter the medical system as an outpatient, and when you have a rare neurological disorder or demyelinating disease, this can be very daunting, especially if your medical state or health state before was relatively simple. You're going to have lots and lots of appointments, at least initially, so your life may start to feel like one big appointment. There will be specialists for different symptoms, different side effects, conditions, so just be aware, and be patient, understanding that you may have more physicians and more therapists than you ever knew you could possibly have at one time. A big consideration is how you get to your appointments. So, if you are now in a wheelchair or using a walker, and this is different from before, you may not have transportation of your own that's able to accommodate that, so there are services and medical transport companies who can provide wheelchair vans or adapted driving areas so that it's easy for you to navigate with your assistive devices or your wheelchair. And depending on your insurance plan, they may cover the cost of that transportation to and from your appointments.

[00:07:58] Another big issue is keeping your calendar up to date because you're seeing so many new people and having to do so many new tests and measures. It's really important to make sure that you have your calendar with you every time you go to an appointment, whether that's as your smartphone, or you're using a good old paper calendar. It doesn't matter. Just make sure that you have it with you because it will be

invaluable for you to set up appointments in a much smoother and easier fashion. Another thing to consider is that your outpatient therapy process is going to be very different than your inpatient therapy process, so it will be less frequent. You'll have less visits during the week. Sometimes that's dictated by your insurance plan, and the focus of therapy at that point is going to be somewhat different than what you did on the inpatient side. So just keep in mind, you're transitioning, and we're trying to get you to back to a better level of function so things will feel different throughout the process.

[00:09:01] You may also have new medications. It's important to stay on top of those. You might have infusions. Sometimes there's confusion about what your insurance will cover. In most of your neurologists' offices, they will have personnel who can help you navigate co-pay assistance for some of these types of things or how you schedule, if you're going to have an infusion, how you schedule that either from an infusion center or in your home. So, there are people who can help you in the community and at your neurologist's office and potentially at your outpatient rehab center, as well. A super important thing is to give your physicians and your therapists honest feedback on how you're doing. We want to be able to help you, and so an honest response to us will enable us to provide more appropriate interventions for you and better support for you to help you navigate this process more easily.

[00:10:03] Finally, in looking at the emotional experience, this is perhaps the most challenging part of the process when being diagnosed with a rare neurological disorder. You can have a lot of mind and body interaction challenges. It's difficult for the mind and body to talk to one another because of the issues in the nervous system, but there are also a lot of emotions and feelings and experiences that may be difficult to handle. Fear, worry, insomnia, fatigue, uncertainty, frustration: These are just some of the things that you may feel, and it's important for you to remember that these feelings are valid. and there are people who can help you to navigate some of this. Some helpful changes that you can do at home, just simple solutions that can help you navigate this, deep breathing is a really good thing to do, closing your eyes, taking deep breaths, and allowing your body to simply relax and your mind to calm, and this will create a sensation of better relaxation and calm but also better airflow, which can help your body.

[00:11:24] Experiencing guided meditation is another excellent tool, and there are many free apps that you can put on your smartphone or tablet so that you can access meditation programs, some of them as short as 5 minutes, to allow you to experience a more calming and relaxing existence for a few minutes to help take you away from some of the fears and worries and the frustrations that you might be experiencing a lot of the time. There are also mental health professionals who can offer guidance in an environment that's designed to help you address your feelings in a safe way. And if you need to access your behavioral health and mental health professionals, your neurologist's or primary care physician's office can help you with referrals or with recommendations to professionals who are in your community that can help you in this way. Again, remember to pace yourselves. Make time for rest. Make time for calming because it will just help your body and your mind to navigate this experience in a much better way.

[00:12:35] And finally, reducing stress and stressful situations will aid your recovering and healing. We know from research and experience that stress taxes the immune system in a very, very bad way. It also can make recovery from significant conditions, severe conditions, much more difficult, so it's important to keep your stress level at a minimum and keep stressful situations at bay if you can. It might mean having a conversation with your family and friends to help them understand how you feel and that you need a calming environment if at all possible. I'd like to say a big thank you to the SRNA for giving me this opportunity to speak with you all today and also thank you to all of you for participating. I'd also like to thank my Barrow team for their input and support for this presentation today. Thank you so much and have a wonderful rest of your conference.

[00:13:40] **GG deFiebre:** Thank you so much, Dr. Campbell. We appreciate it.

[00:13:43] **Dr. L.A. Campbell:** Thank you.