

Love Stroke: Stroke Recovery and One Young Couple's Journey

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If We Only Knew: Warning Signs and Actions

- An easy acronym to remember for stroke warning signs is FAST, which stands for face, arms, speech, and time.

F: Ask the person to smile. Does one side of the face droop?

A: Observe the person's arms. Arm weakness or the inability to hold both arms up is another sign of stroke.

S: Listen for slurred or strange speech and other speech difficulties.

T: If you notice these symptoms, it's time to call 911.

If We Only Knew: Awareness and Advocacy

- There were signs we should have had checked out, including recurring mild headaches, anxiety and fatigue. If you have these symptoms, go to the ER or see your physician as soon as possible.
- There are activities and medicines correlated with stroke in young women. Taking birth control, taking pseudoephedrine, and smoking over many years are all possible risk factors.
- Consider that a stroke requires neurological care, and if your hospital is like the first hospital we went to, it won't have the specialized care that can make such a difference.

If We Only Knew: ICU 101

- "Nothing good happens fast in the ICU." This saying could not be truer, so as difficult as it might be, you have to be patient and keep a clear head. You will receive a lot of technical information to digest and could have to make an important decision any minute.
- The ICU will assign a caseworker to help you with many aspects of care, including navigating the hospital and identifying options for what happens after the ICU. Seek out your caseworker proactively to discuss and plan options.
- Make use of social media and Internet resources. During the many hours of waiting, use social media to keep friends and family up to date so that you don't have to repeat the same information to different people.
- You will be digesting a lot of new information and medical jargon. Do research online to make sure you understand it. You might find it helpful to write things down and keep all the information together in a folder.

If We Only Knew: Inpatient Rehab Tips

- Things move fast. Unlike in the ICU, good things happen fast in rehab. Their goal is to get the patient out of rehab, and the only way out is independence or as close as the patient can get to independence in a matter of weeks.
- Get to know the staff. Just as in the ICU, getting to know the nurse's aides, nurses, doctors, and therapists is critical.

- Have patience. Communication, lack of memory, and cognitive and physical limitations are common for TBI victims. They will be frustrated, and so will you. In most cases, they are still figuring out what happened, so be patient, and be careful with tone of voice and stimulation levels. Less is more in the early days and weeks.
- You will need a quarterback. The hospital staff will not coordinate, communicate, and organize everything for your loved one, and the first week is critical in terms of getting the lay of the land and understanding the daily regimen and goals. Document the names, specialties, and affiliations of the doctors and nurses. Keep a list of medications, test results, and any progress or therapies. Know when visiting hours are and when the doctors are expected to visit the patient so that you know when to be there to ask questions on behalf of the patient.

If We Only Knew: Welcome Back

- Pictures and names are helpful. Memory will likely be affected, so bring pictures of family and friends for the room, and go over them with the patient to try to help him or her re-create familiarity and know who is visiting. Importantly, the patient might not know you, so prepare yourself and help him or her.
- Rest is essential. When the patient is between therapy and tests, rest is the most important thing for the brain to heal and the person to recover for the next day's activities. Just like after a workout, your muscles need to rest. The same goes for the brain.
- Overstimulation is counterproductive. As much as everyone wants to maximize visiting hours to show support, what the patient needs is carefully controlled visitation and one or two people max talking and interacting. This is especially true if the patient was asleep for several weeks, as Kelly was.

If We Only Knew: Therapy and Surgery Insights

- Don't panic. Watching your loved one struggle and fail to do basic things is terrifying, but the brain relearns skills faster than it learned them the first time. An ability can come back quickly once a new pathway is found, but it takes trial and error.
- Be an active participant. Teaching the brain to relearn things requires repetition, and the therapists only set the table. It's up to the patient and his or her caregiver to practice and do homework to improve. Plus, at some point, you will be home and have to lead the activities if you want your loved one to improve.
- Remember that improvement is infinite. You might have limited time in the rehab facility, but your brain will never stop improving.

If We Only Knew: Going Home

- Map out a daily routine. It's important to think through all the little things that happen throughout an average day and think about whether your home is equipped to facilitate these activities. An occupational therapist has a special role in stroke rehabilitation. His or her expertise includes identifying modifications to an environment to accomplish a task, identifying accommodative technologies, developing strategies, and assisting with evaluations. An occupational therapist will usually visit your home and recommend adaptations before you are released. If that is not the case for your facility, request the visit anyway.
- Think about basic safety. Install grab bars in the shower and around toilets, add railings on the stairs and places where the wheelchair or cane will not be stable. You need a checklist to

identify safety risks and assess upgrades needed, including wheelchair access, railings, stools and chairs, temporary or permanent grab bars in the bathroom and shower, steps required, mirrors and sinks, cabinets and tables, and a way to get to vehicles from the house. Develop this checklist in conjunction with your occupational and physical therapists.

- Find a medical supply store. There's probably one near you. Such a store will have canes, wheelchairs, grab bars, braces, motorized scooters, walkers, and most anything you need. Most importantly, it will lease most large items for as long as you need them, and the lease should be covered by your health insurance. Your health savings account is a great asset too.
- Know the pharma regimen. Have the pharmacology instructions written down and electronically available. Know what each drug does and what the goal is in terms of ongoing care or slowly reducing the schedule to zero. Understand warning signs that reduction is too fast and side effects of improper dosage. Keep everything together in your file so that anyone on your recovery team can access and read the information.

If We Only Knew: Visitors at Home

- Ensure all the items on the homecoming checklist are complete. Safety first!
- Be sure to take advantage of any caregiver training sessions before returning home and after, if appropriate. Caregiver support groups not only are a wonderful break but also can give you ideas you haven't thought about and help identify resources you didn't know existed.
- Don't have a party. We made this mistake. Patients need to slowly get used to their houses again and get comfortable at their own pace. Although everyone wants to see them, they can likely take only a few visitors at a time over several weeks. The best thing friends and family can do is be patient.
- Rest. Rest is still important for the stroke survivor. Don't be afraid to tell visitors that the survivor needs to rest and that it's time to go.
- Be aware of the invisibility phenomenon. People won't mean to talk about the patient in front of him or her, but they will. Either talk to the survivor directly and patiently, or don't talk about him or her at all. Eventually, people figure it out, but it's hard, as they want quick and detailed responses, which are impossible. They need to save all the medical questions for another time and be happy just seeing and spending time with the survivor.

If We Only Knew: You Are in Charge

- Develop a one-arm wardrobe. It sucks, but if you've had a stroke, you need to overhaul your wardrobe if you want to be independent. That means no more heeled shoes, button-up tops, laced shoes or necklaces. It might not be forever, but T-shirts, sweats, and slip-on or Velcro gym shoes are the easiest.
- Recognize the difficulty of a one-arm kitchen and laundry. If you need two hands to do a task, then you need an alternative plan. Sometimes adaptive tools can help and you can ask a family member to help so that you can focus on getting better.
- Keep records. You will need a binder, probably several. Over time, you will build in-depth records for therapy, medicine, health insurance, disability, social security, legal guardianship, and Medicare. These will all become sections of the binder.
- Make sure you have communication details. Get the names, e-mail addresses, and phone numbers of key people, and keep them in the file. As long as you don't abuse the privilege, you might be able to e-mail or text questions and get answers faster than if you were to call

and leave a message.

- Be aware of seizure risk. Ask about the risk, and know the signs. Create a plan in case a seizure happens.

If We Only Knew: Coming to Terms

- Accept your new normal. Finding your source of motivation will be important to moving forward in your recovery, but it will take time. As the first few months go by at home, recognize that things will continue to change, and progress is not always linear. Some days will be better than others. Whatever your new ambition is, it will help you through your day-to-day limitations.
- Give the patient time. As a caregiver, you might realize early on the likely limitations the person will face, but you need to let the stroke survivor come to terms with it at his or her own pace. Positivity and encouragement are what is needed. That said, you must plan accordingly in terms of your finances and other household needs.
- Don't neglect caregivers' care. Initially, most caregivers don't mind giving 100 percent to allow a stroke survivor to recover, but as time goes on, the demands of working and taking on caregiving tasks can feel like too much. In the beginning, there might be a lot of offers for help. Accept them, because these offers can decrease as time goes on. Think about what you can delegate so that there isn't such a heavy load on the caregiver. Think about what you're going to need in the long term, and research how to get it. Caregiver support groups can help with this as well.

If We Only Knew: Setting Goals Is Tough

- Small wins add up. You have to set goals in rehab and therapy that are attainable. It takes time, but small wins add up. Things like climbing a step, kicking a ball, and saying and writing a word are big small wins. I set weekly goals for myself that went beyond my therapy goals. Speech, occupational, and physical therapy all translated to things at home I had to relearn, and I wrote them all down in my goals book and checked them off as I relearned how to do everyday activities and increase my vocabulary. You might have other small real-life goals. Try to achieve them while remembering that it can take time and patience to do so.
- Seek out specialist testing. For whatever reason, no one recommended we see a neuropsychologist until well into outpatient therapy, so we didn't know the full extent of cognitive damage, nor did anyone test Kelly's sight or hearing, as an eye doctor or ENT specialist would. Our advice would be to push for these assessments early so that you can understand the full extent of any damage that might not be visible to the naked eye. Don't assume the tests have been done.
- The neuropsychology evaluation is an important step in understanding long-term cognitive capabilities, including analytic and arithmetic logic and skills. The results will likely be demotivating at first, but they are important in helping the patient and caregiver face the reality of what has happened. The doctor will also assess the patient's overall attitude, state of depression or grief, and likely future mental capacity and outlook. On a practical note, the assessment will be required when you apply for short- and long-term disability benefits.
- Setting limits is important. As you come to know the new person you've become after a stroke, don't be afraid to ask for counseling if you need it. It's a huge emotional shift to need to recover, and needing help is normal. It's also normal to set limits in your relationships. There are some things you cannot do, but there are also some things you might not want to do. Communicate these limits kindly, and seek the advice of a therapist if you need help doing so.

If We Only Knew: Travel Strategy

- Be aware of the challenges that airports present. Even if you don't need a wheelchair on a daily basis, airports are different. You should indicate wheelchair assistance in your itinerary and research the terminals and gates. Don't be afraid to tell TSA you have a handicap. If you walk, be aware of the crowds of people, as they will knock you over if you can't see them coming.
- Carefully research hotels and resorts. As you plan your trip, scout the layout of the resort or hotel on the Internet. Make sure the shower in your room has grab bars or is a walk-in. Ask for a room by the elevator or the areas where you plan to spend the most time.
- Look for railings in and around pools and beach access, and let the staff know before you arrive that you have some limitations. These little things will add up to a better trip, as your handicap will be less of a distraction.

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