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A Second Chance: A Patient's Perspective

By: Cyndy Collins MSN, FNP-BC

Liver Transplant is a life-saving procedure and for those waiting for an organ transplant. It is a second chance at life. Organs are offered to potential recipients based on their 'Model End Stage Liver Disease', or MELD, score. This is a score calculated using certain lab values. The score may range from 6-40, with 40 being the maximum score; the higher the MELD score, the sicker the person. People are referred for transplant evaluation once they have a MELD of 15 or higher. Organs are allocated to the

people with the highest MELD score. People who have liver cancer may qualify for MELD exception points, which can boost their MELD score.

People awaiting a deceased donor organ transplant often wait 1-2 years for an organ to become available. In our experience at UC San Diego Health, the majority of liver transplant recipients are very grateful for the precious gift they receive. This patient interview highlights a patient's perspective of his journey through the transplant process and care continuum.



Cynthia (Cyndy) Collins, MSN, FNP-BC

is a Nurse Practitioner on the Liver Transplant Team at UC San Diego Health. She earned her master's degree/NP from University of San Diego. She has over 30 years of experience as a Registered Nurse and over 10 years of experience as a Nurse Practitioner.

She joined the Liver Transplant team at UC San Diego Health in 2008. In addition to being a pre-liver transplant Nurse Practitioner, her experience includes management of post-liver transplant in adults, pre- and post-kidney transplant in pediatric and adult patients. Additionally, she has many years of experience in management including regional director for dialysis centers in Southern California. Most recently she participated in the 12th Annual Evidence Based Practice Institute: Consortium for Nursing Excellence in San Diego on a project geared to raise immunization rates in patients awaiting liver transplantation. She loves to travel to foreign countries, walks on the beach, hiking, Soul Cycle and Orange Theory.



Dalia Iniguez, AA, Aldo Briceno, Cyndy Collins, NP

Aldo's Story

Aldo Briceno is a 63 year-old male with a history of Hepatitis C and alcohol abuse. Aldo was diagnosed with liver cirrhosis in October 2017 at the same time he learned he had Hepatitis C. Shortly after his diagnosis of cirrhosis, he was diagnosed with Hepatocellular Carcinoma (HCC), a complication of cirrhosis.

In July 2018, Aldo was referred to UCSD for a liver transplant evaluation. He began the arduous liver transplant evaluation process that August. In September, Aldo underwent a Trans-Arterial Radioembolization (TARE) procedure to treat his liver cancer. Tired and overwhelmed by his illness, Aldo and his wife Linda

decided to take the month of October off to travel in their motor home, escape the medical industrial complex and seek solitude.

Unfortunately, Aldo's liver function deteriorated after the TARE treatment. He developed other complications associated with his liver disease. He required regular large volume paracentesis, a procedure used to drain the fluid that accumulated in his abdomen. Additionally, he occasionally felt confused secondary to toxins building up in his blood stream that affected his mental status. His liver was no longer able to effectively perform the vital function of filtering and detoxifying. By Christmas time, Aldo was feeling

quite ill but remained hopeful. He was listed for liver transplant on 12/21/2018.

Although the treatment he received for the liver cancer had been successful in some part, he developed several other small cancers. He was unable to undergo further loco-regional therapy due to worsening hepatic function. He remained within transplant criteria... barely. His window for transplant was closing. He made frequent trips to transplant clinic, had frequent imaging and frequent lab tests. The clock was ticking. On June 19, 2019, Aldo received the call that all patients wait for: A liver had finally become available. It was Aldo's turn to get a second chance at life.



Aldo Briceno before his liver transplant.



Aldo stopping to smell the flowers after liver transplant.

Aldo's Interview

NP: What were you most concerned about while waiting for a liver transplant?

Aldo: I worried that we were not going to get a liver in time. "Would there be a liver in time for me to survive? Will my MELD score ever be high enough to get an organ offer"?

NP: Sometimes when people are ill they have fears that they keep to themselves. What were some of your fears?

Aldo: I was afraid that I would not be able to see my wife, my kids or grandkids. I knew death was a possibility before being transplanted. I was not afraid of dying. I wanted to know how fast my cancer was growing.

NP: Describe some of the feelings you experienced during your journey.

Aldo: I asked myself why me. What did I do to deserve this? I was in denial at first. I was hoping to hear something different than what was real. I experienced loneliness and sadness. I cried at times. I felt isolated.

NP: At what point do you think you accepted your disease?

Aldo: I think that I accepted my disease process somewhere in the middle of the road. Likely sometime after my radiation in July. I was confused about the outcome. The radiation I had received for the liver cancer had also [negatively] affected my liver function. I accepted that I was going to die.

NP: How did your illness affect your day to day life?

Aldo: My illness affected my life tremendously. I could no longer do the things I enjoyed doing. I could no longer work in my yard due to my exhaustion. I was unable to run. I could no longer tolerate being out in the sun.

NP: Tell me about what you had to give up because of your illness and how that impacted your life.

Aldo: My dream was to retire and travel in my RV. I retired and was diagnosed with liver disease and found out that I had liver cancer. Travel was put on hold. Many aspects of my life were put on hold.

NP: How did your illness affect the important people in your life?

Aldo: It's really funny how my illness affected the people in my life. Some of my family and I grew closer together. My brother and his wife came every weekend from Cerritos to see me. I know it was a hardship for them but they came anyway. My wife worried and still worries about me often.

NP: What goals do you have in your life now?

Aldo: My goal is to enjoy people every day. Live life to the fullest every day. Do not harbor hate. Be forgiving.

NP: What would you like to say to your audience and to other people waiting for an organ transplant?

Aldo: Be thankful. Be happy. Don't take anything for granted. Accept your illness and be at peace with yourself. Be honest with yourself. If you don't make it to transplant, there is another world. A spiritual world. If you believe in God, you will be in heaven. Faith will get you through.

I want to give a special thank you to Dr. Vodkin for taking care of me. She is an amazing doctor. I'd like to thank the entire team for caring for me. Everyone has been awesome! The nurses in the hospital never missed a beat. I was embarrassed when they had to clean me up. The nurse never batted any eye, while all along saying "no worries, it's my job".

NP: Now that you were given a second chance at life, tell me what you are doing with your life?

Aldo: I am giving back! I am caring for a 79 year old friend of mine that has colon and liver cancer. He has chosen not to pursue any medical treatments. I visit him every day. I cook for him. I clean his kitchen for him. Most of all, I keep him company so that he is not alone.

I get out and work in my garden. Something I really enjoy doing.

I plan to write a letter to my donor family to express my gratitude for this wonderful gift that I was given.

Caregivers are an integral part of the transplant process. Each transplant candidate must have a committed caregiver and a solid care plan prior to being listed for liver transplant. Aldo's spouse Linda was his caregiver. She shared the following:

Linda: First of all, I want to say that it was an honor to take care of Aldo. It was the hardest thing I have ever done. I had experienced some tragedy in my life when I was younger and thought to myself, this cannot be that difficult. It was very tiring. I seriously had no idea how much work was involved until I did it. No matter how many times I was told that caring for a transplant patient would be difficult and a lot of work, I did not really understand that until I did it. It was frustrating. I often times wondered if I was doing things right and was I doing enough. Waiting and waiting was scary and frustrating.

If I had to give someone else advice about the process I would say: use your resources. Allow other people to help. Do not try to do this all by yourself. Ask a lot

of questions. I was very thankful that I was able to call the transplant team while we were waiting and ask questions. If we lived closer to UCSD, I think it may have been a bit easier. I could not have done this without the support I received from the team. The reward outweighed the frustration. It was all worth it. We are putting our lives back together. I would do this all over again if needed. I would say to anyone going through this, appreciate everyone. To the women who cleaned Aldo's hospital room every day, thank you. To the employee in the cafeteria who made sure I ate every day and showed concern for me, thank you. To the nurses who cared diligently for Aldo every day, thank you. To the surgeons, all the doctors, student doctors and nurses, we appreciate you all.

Words of Acknowledgement

for Transplant Nurses from our Solid Organ Transplant Physician Team

Our organization enjoyed tremendous success in the transplant arena over the last few years with 2019 being the year when several transplant programs set the record for the most transplants ever done at UCSD with amazing outcomes. This feat was made possible by tremendous commitment of every member of the transplant team and our nurses in particular.

They have taken care of the numerous sickest, most challenging patients, that were deemed “non-survivable” by outside hospitals. These are the nurses who sometimes literally carried physically debilitated patients during the Physical Therapy sessions, who stayed after their shifts were over to make sure the patients did OK, that woke up in the middle of the night to come in and to take care of the patients on ECMO, that followed with the challenging patients and to make sure their immunosuppression plans were carried out to perfection. Our nurses also contributed greatly to the fund of knowledge and research in the transplant arena as demonstrated by the articles published in this issue of the journal. All UCSD Transplant teams celebrate the success of 2019 and are looking forward to 2020 with confidence supported by the quality of nursing staff taking care of our transplant patients.

Eugene M. Golts, MD

Associate Clinical Professor
Division of Cardiovascular and
Thoracic Surgery

We want to express our deepest gratitude to our nursing teams both on the inpatient and outpatient side. There is a tremendous amount of effort that goes into getting a patient through the transplant process and our nursing colleagues are amazing at doing this. For patients, their nurse coordinator is their link to the transplant center while they wait months and years for transplant. These nurses form incredible bonds with their patients as they guide them through their transplant process. Our post-transplant nursing team tirelessly works to help patients understand their complicated medication regimens and educate them on how to keep themselves healthy. The UCSD transplant programs are thriving and our patients are thriving along with it- it could not be done without our amazing nursing colleagues.

Mita Shah, MD

Medical Director, Kidney Transplant and
Living Donor Kidney Transplant Program

We want to congratulate our nursing teams at UCSD with this publication and express our sincere appreciation for the care they have provided our patients. We know that caring for the sickest of the sick and facing situations with little or no hope can weigh heavy on our nursing staff. It is when faced with these situations that the real human nature of caring for and nursing the sick back to health shine through the brightest. UCSD transplant teams boast some of the best outcomes in the nation and we acknowledge that this is in no small part due to excellent nursing care. The future is bright if we give our unbridled attention to our patients. The reward of nursing the sick back to health is worth it!

Victor Pretorius, MBChB FRCS

Professor of Clinical Surgery
Division of Cardiovascular and Thoracic Surgery
Surgical Director Heart Transplant and MCS Program
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Organ transplantation epitomizes the need for team medicine and our nurses are the patient’s advocate as they navigate the complexities of transplant. Numerous liver transplant candidates at UCSD with limited resources have been supported through successful liver transplantation largely due to the attentiveness and dedication of our nurses. Our nurses are patient, approachable and empathetic and always go above and beyond to support our patients. It is an honor to work alongside our exceptional nursing colleagues to care for our transplant patients.

Veeral Ajmera, MD, MAS

Assistant Professor of Medicine
Medical Director of Liver Transplantation
Division of Gastroenterology and Hepatology

We are so proud of our transplant program which saved over 300 lives last year. This is not only a record number of transplants for UC San Diego but a record for a program in San Diego as well. This is only possible because of the dedication and competence of our transplant nurses in the pre, peri-operative and post-operative arenas. We want to recognize our nurses for the tremendous efforts they have put in to provide exceptional care for our patients. Our whole team realizes that transplant care often requires personal sacrifice and time away from our families and friends to make successful, and we truly appreciate and applaud our nurses for that commitment.

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