

It Takes a Village: Preparing your support plan for transplant care

This webinar will start shortly. It will be recorded and the slides will be available at www.dpcedcenter.org

Next webinar: March 28th at 2:00 pm Eastern
Get Your Sweat On! Exercising for Healthier Kidneys

Reminders

- ▶ All phone lines are muted
- ▶ **Unmute: #6** to ask questions at the end of the presentation
- ▶ **Mute: *6** after your question
- ▶ Or, ask questions through the Chat Box
- ▶ You will receive the link to the **recording** and **slides** by email
- ▶ Please complete the feedback form at the end of the program

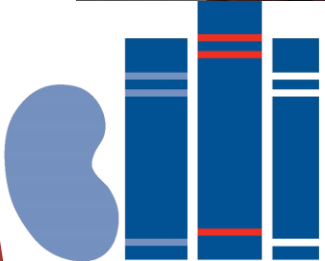


Today's Presenter

Lara E. Tushla, LCSW



- ▶ Outpatient dialysis social worker for six years
- ▶ Kidney and Pancreas Transplant Social Worker since 1998 at Rush University Medical Center Transplant Program
- ▶ Writes articles and does presentations for patients and professionals





Transplant Candidacy

- There are a lot of factors in determining if someone is a transplant candidate
- Policies and guidelines are based on evidence based standards of care, governmental policies, insurance criteria, and the experience of the center
- While many criteria are standard across transplant centers, some are center specific
 - Can always get a second opinion from another center

Oversight

- Centers for Medicare and Medicaid Services (CMS)
- United Network on Organ Sharing (UNOS)
- Department of Public Health (state based)
- Hospital Quality Improvement Department
- Program specific policies, procedures and quality initiatives
- Commercial insurance company guidelines

Rush University Transplant Policies and Guidelines in relation to Social Work

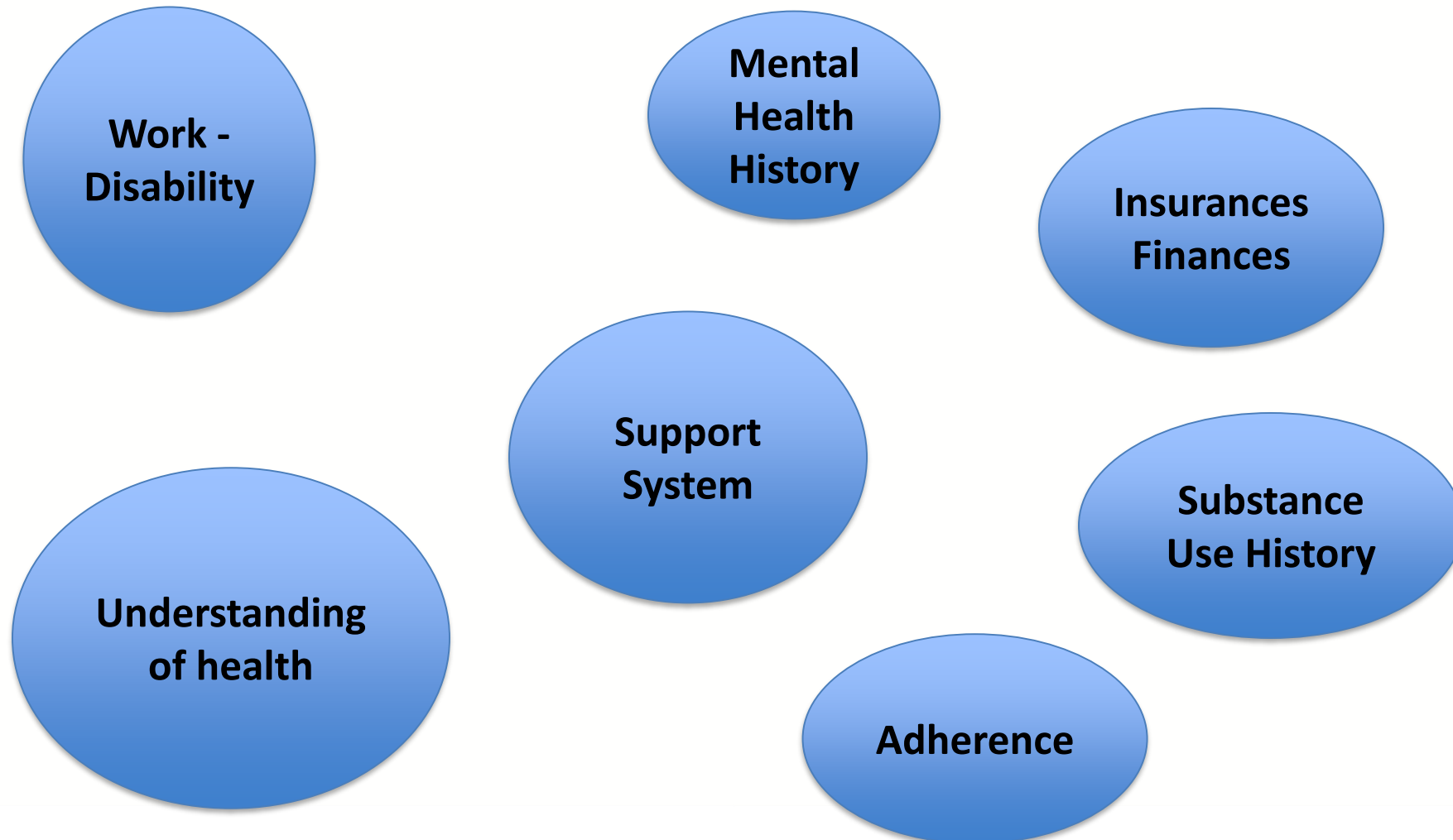
- **Kidney Recipient Selection Criteria**
 - **Inclusion:**
 - Ability of patient and patient's support system to comply with medications and follow-up visit protocol.
 - **Relative Contraindications:**
 - Limited social support
 - Confirmed history of non-compliance with medical recommendations – **may have to document improvement prior to completing testing**
 - Evidence of uncontrolled mental illness – **must be treated first**
 - Current drug or alcohol abuse – **must be treated first**
 - **Absolute Contraindication:**
 - Inadequate social support
 - Diagnosis of Alzheimer's Disease or dementia confirmed in medical record

Who meets with the social worker?

- Everyone!
 - Before listing for transplant and periodically while on the waiting list, everyone has a comprehensive psychosocial assessment.



Psychosocial Assessment



“Perfect” Transplant Candidate

Attends every dialysis treatment... for the full prescribed time

Keeps all medical appointments... without reminders from the staff

Takes medications perfectly... 100% of the time

Manages own health... tests blood sugars, checks vitals, healthy weight, exercises

Reaches out for assistance when needed

Arranges own transportation... and has a backup plan (or 2 backups for bonus points)

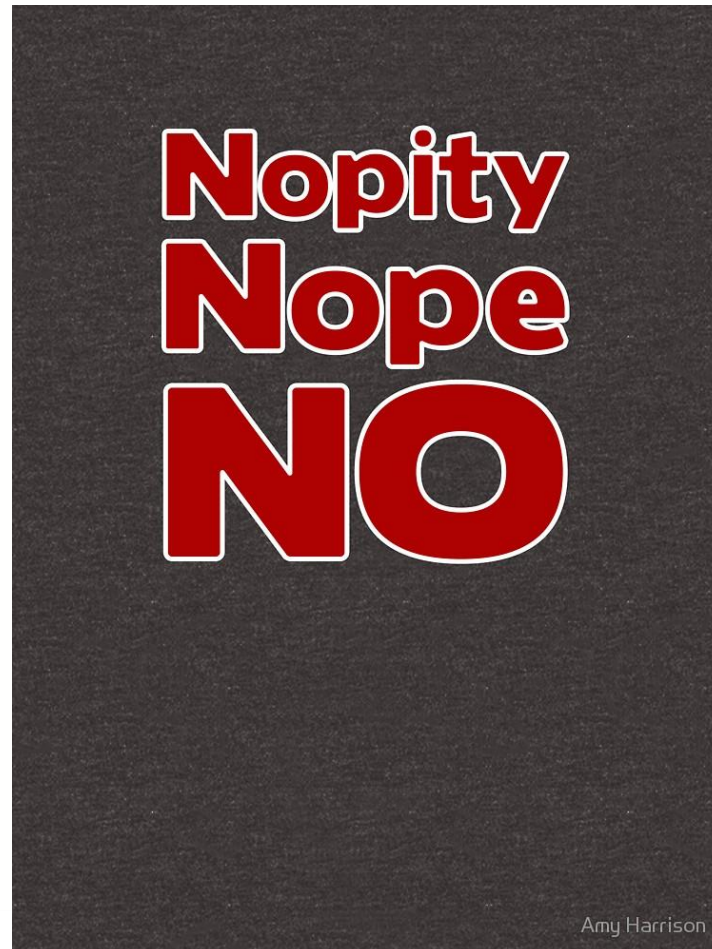
If the person has a mental health or substance use disorder history... is now or has been under the care of someone for that. Has good insight and knows how to reach out for additional care when needed

Lives life to the fullest now... and has plans for doing more things after transplant

Has a robust support system... with backup caregivers

Have I found the “perfect” transplant candidate??

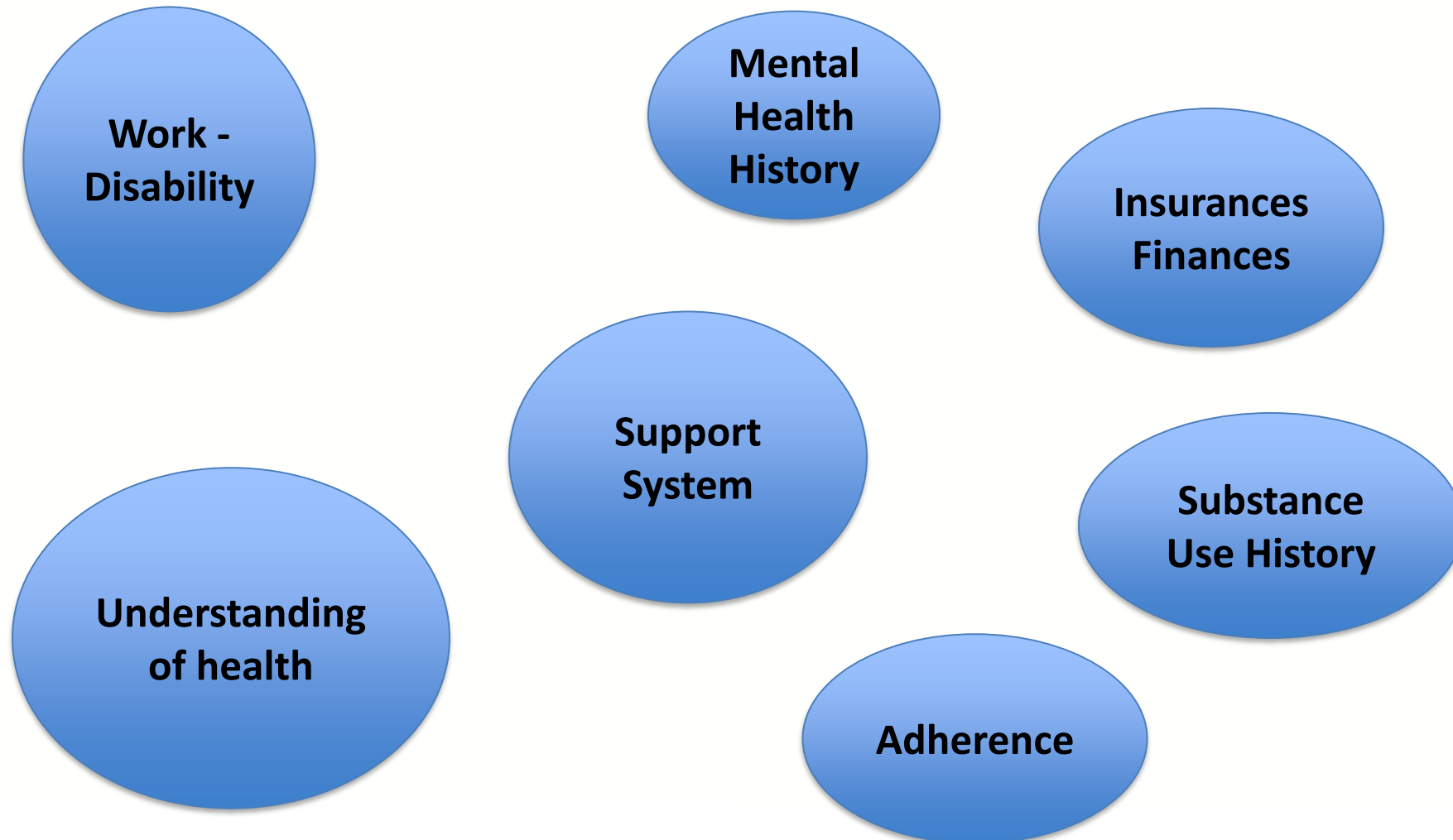




Why Not?





Psychosocial Assessment



After the Social Work (Psychosocial) assessment ...

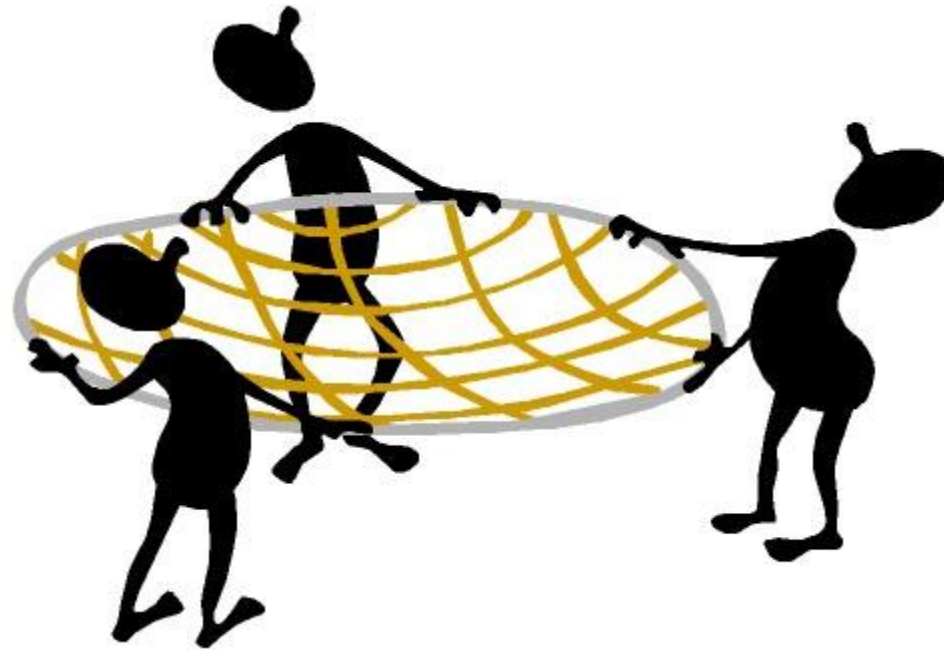
- **Plan for the patient**

1. Cleared and ready to go 
2. Not a candidate 
3. Homework to become a candidate
 - Mental health/substance use treatment
 - Improved adherence
 - Support system development
 - Insurance matters
 - **Then Re-Evaluate**

MAYBE

**Probably the Number 1
reason people don't get
Social Work clearance for
transplant, in my
experience...**

Lack of Support System



What's the
Big deal?

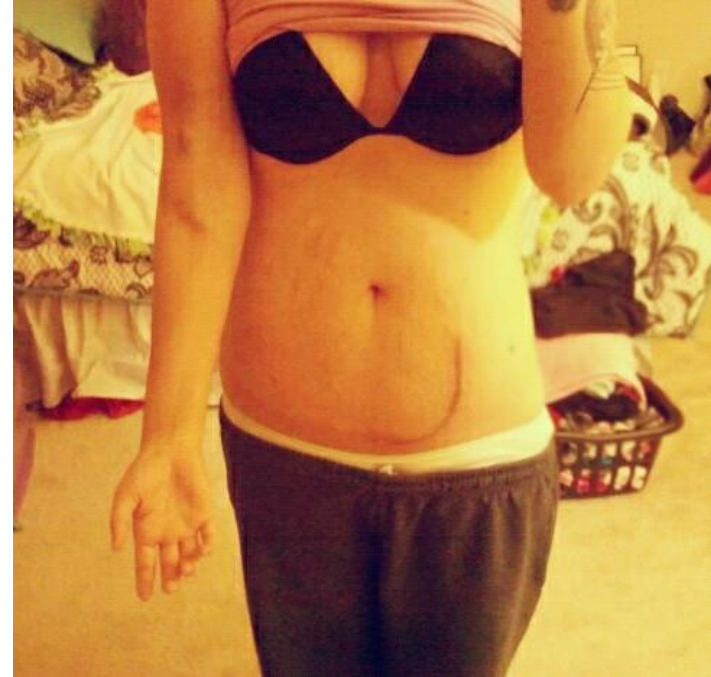
Why is a Support System Important?

- **I AM INDEPENDENT...**
 - Take myself to dialysis
 - Manage my medicines and appointments
 - Handling household responsibilities

So Why do I Need Support??

**It is not a matter of
questioning your abilities
now...**

**It's the reality that everyone
needs some help after major
surgery...**



Everyone needs help

- Surgery is several hours long
- Relatively short hospitalization (3-5 days)
- Anesthesia, pain medicines, high dose steroids, and not sleeping well can make it hard to learn
- Can't drive for a couple weeks, maybe longer

- Typically have a 10lb lifting limit for a month after the surgery so the muscles can heal. Otherwise can get a hernia at the incision... more surgery... big set back.
 - 10lbs is a gallon of water, so not carrying groceries, laundry, garbage, yard work, carrying children, pet care
- We use our stomach muscles for EVERYTHING
 - Sneezing, laughing, coughing, going to the bathroom, driving, turning... will cause some pain

On the other hand, You are not an invalid

- Typically sitting in a chair and walking in the room a little the day after surgery
 - And are more mobile every day
- Learn how to care for the transplant
- Go to the bathroom and shower independently
 - Probably want someone in the home the first time you are doing these things as you figure out how best to do it
- Can do light cooking

What does the support system need to do?



Support System

- **We need the support system to:**
 - Able to come to the hospital while person is admitted to learn about medications and caring of the new kidney and/or pancreas
 - Able to be able to take time off for appointments for a few weeks
 - Either stay with the patient or the patient stay with support person for up to a month

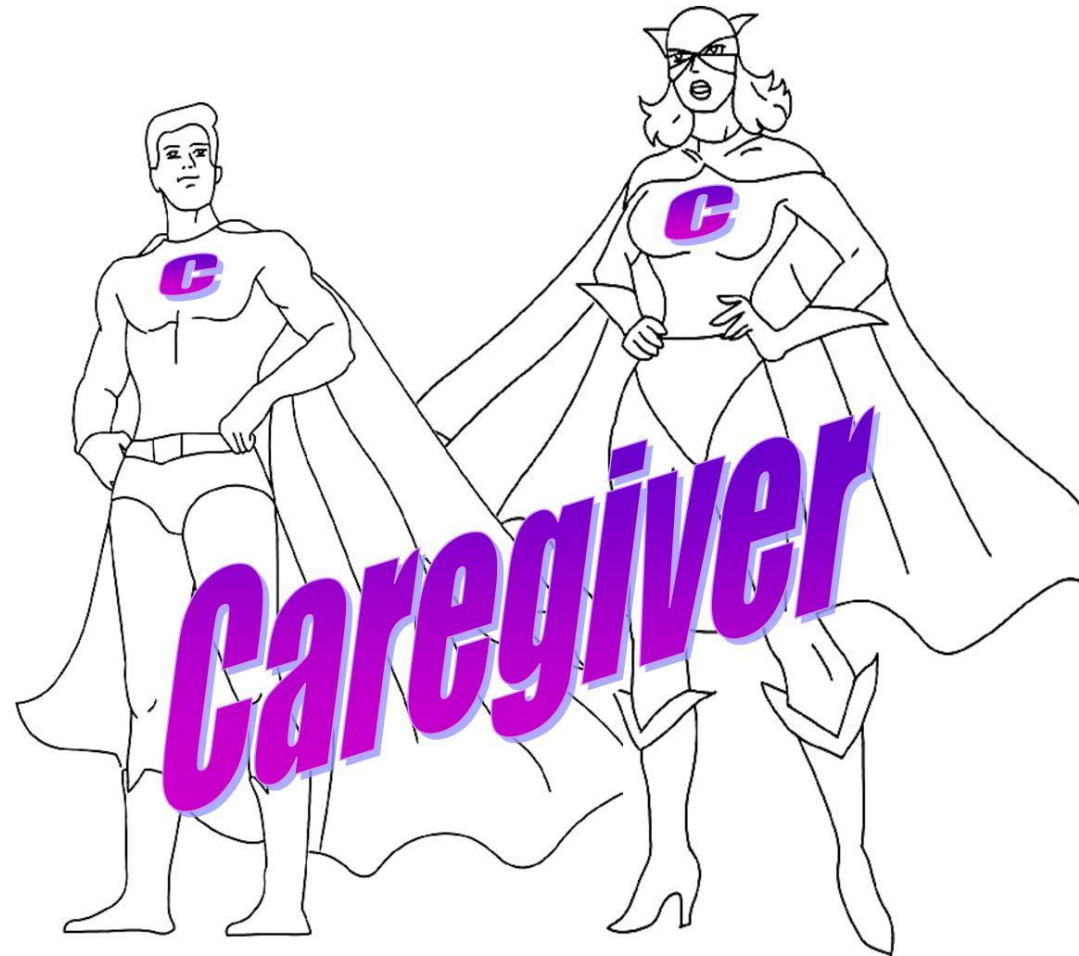
Support System

- Able to help manage medications, especially right after transplant when doses change often
- Either drive, find driver, or coordinate transportation services (Medicaid, transportation services for people with disabilities, Uber/Lyft)
- Able to take over household chores for at least a month due to the 10lb lifting restriction
- Take over other responsibilities that the patient does, like child care, pet care, elder care

Support System

- Help recognize when recipient is sick (fever, vomiting, UTI) and call the office if there is a problem.
- Help reach out to the Transplant Team if there are problems with accessing medications, insurance, appointments, etc.

Doesn't have to be...



Support System

- Doesn't have to be...
 - One person
 - In fact we prefer if it's more than one
 - Blood or marriage relation
 - Medically trained
 - Able to take a month off of work
 - Super strong

One size does not fit all

You might be surprised...

What's worked

- Neighbors
- Church family
- Extended family
- Ex-spouse
- Coworkers

What's failed

- Spouses
- Adult children
- Siblings
- Parents
- Paid caregivers

Things I've learned

If it's a group of people helping

- Put someone in charge to coordinate. Minimize duplication of services. Reduce stress for everyone
- One point person for talking with the transplant team (with patient), less chance of mixing things up
- If multiple people are helping, use a notebook that everyone can add to
 - Took meds at 9am
 - Temp at 8am was 99.8, took Tylenol

Scenario #1

Should have worked...

- 68 yo gentleman
 - Single, no children
 - Lived downstairs from his sister and brother in law.
 - Two nieces are nurses and live close by. They have been involved in his care for years.
 - After transplant, he had urinary tract infections. Became more frail.

- Ended up in a skilled nursing facility
 - Staff at the skilled nursing facility had difficulty giving his medicines “on time.”
 - Medications were changed to ones on the formulary of the facility. We were unaware of the changes until he was admitted.
 - Very difficult to get him into our office for visits.
 - He became even less active and more frail.
- Eventually passed away
- Transplant lasted less than a year, much of which he was hospitalized or in the skilled nursing facility.

Scenario #2

Could have failed

- 59 year old woman
 - Single, no children
 - No family
 - She said that she had close friends in her building that would help.
 - Had a meeting with the patient and a couple of her friends.
 - Reviewed the things that the supports would need to be able to help with. They developed a plan to cover those needs.

- One friend took charge to coordinate everyone else.
 - Drivers, help with medication management, meal prep, household chores
- Over the years when she's been sick, her friends have stepped up.
- Has had the transplant for 3 years and is still doing well.

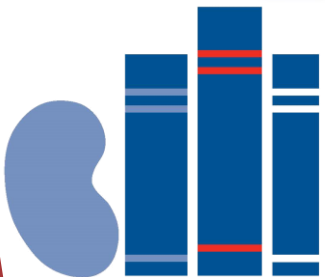
Collaborate with the Transplant Team

- Understand if you have and specific needs to plan for.
- If you aren't sure who to ask, your dialysis or transplant team may be able to help you think through some options
- Have the support system meet with the transplant team.



Questions?

Chat box or unmute phone line #6



Thank You for Attending Today!

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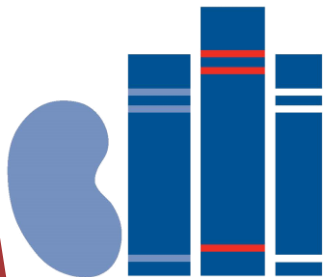


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Presented by Collette Powers, Renal Dietitian



Learn more and RSVP at
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