



Preparing and Supporting the patient and family for a Renal Transplant



**Texas Children's
Hospital®**

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Disclosures

- None

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I have been a CCLS in the renal department since 2011, and currently work as the primary hemodialysis child life specialist.

This session will discuss the unique role of the child life specialist in preparing the patient and family for a kidney transplant, from initial diagnosis to transplant admission, and supporting them throughout their transplant journey.

GOALS:

- Provide Overview of Transplant Process from diagnosis through transplant admission
- Discuss psychosocial challenges of transplant
- Explore Child Life Specialist's role within the multidisciplinary team
- Share techniques, tools, and resources used to provide developmentally appropriate preparation, education, and support

The Road to Transplant

There are many paths from diagnosis to transplant. Depending on a patient's renal function at diagnosis, they may go through any/all of the following stages:

- Outpatient Renal Clinic
- ESRD, requiring dialysis
- Transplant Listing (preemptive or while on dialysis)

Outpatient Renal Clinic

If a patient is diagnosed with Chronic Kidney Disease (CKD) but does not yet need renal replacement therapy in the form of dialysis or a transplant, they are seen in the outpatient clinic for regular labs and follow up

ESRD, Requiring Dialysis

When a patient reaches End Stage Renal Disease (ESRD) they are no longer able to safely function without dialysis. At this point, a patient will choose between hemodialysis and peritoneal dialysis and begin treatment.

Transplant Listing

A patient can be listed before starting dialysis (pre-emptive) or while on dialysis

- A pre-emptive listing may help a patient avoid dialysis, or only spend a short amount of time on dialysis, especially when there is a living donor available
- A patient who is listed while on dialysis will receive “credit” on the transplant list for the time they have been on dialysis

Transplant Work Up

- Transplant work up includes a variety of tests, labs, imaging, procedures, meetings, and interviews with the medical team, which includes the multidisciplinary team
- At the end of this process, a patient is presented to the Medical Review Board (MRB), and if approved, they are either placed on the deceased donor wait list, or the team moves forward with scheduling a living donor transplant.

Renal Transplant Evaluation Checklist	
Patient Name: _____	Parent/Guardian Names: _____
MRN: _____	_____
DOB: _____	_____
Diagnosis: _____	
<u>Consents</u>	
<input type="checkbox"/> Evaluation Consent: _____	<input type="checkbox"/> Uric Acid
<u>Records</u>	<input type="checkbox"/> Mg
<input type="checkbox"/> Social Security Card (if applicable)	<input type="checkbox"/> Phos
<input type="checkbox"/> Immunization Record	<input type="checkbox"/> Total Protein
<u>Evaluations</u>	<input type="checkbox"/> Albumin
<input type="checkbox"/> Medical: _____	<input type="checkbox"/> LDH
<input type="checkbox"/> Urological: _____	<input type="checkbox"/> Lipid Panel
<input type="checkbox"/> Social Work	<input type="checkbox"/> Iron Panel
<input type="checkbox"/> Child Life	<input type="checkbox"/> HgA1C
<input type="checkbox"/> Dietitian	<input type="checkbox"/> Serum HCG (females with childbearing capacity)
<input type="checkbox"/> Financial Counselor	<input type="checkbox"/> CMV IgG/IgM
<input type="checkbox"/> Pharmacy	<input type="checkbox"/> EBV Panel
<u>Procedures</u>	<input type="checkbox"/> HSV IgG/IgM
<input type="checkbox"/> Chest X-Ray- PA/Lat	<input type="checkbox"/> Toxoplasmosis IgG/IgM
<input type="checkbox"/> VCUG with KUB	<input type="checkbox"/> HIV Diagnostic Panel
<input type="checkbox"/> Renal US	<input type="checkbox"/> Hepatitis Diagnostic Panel
<input type="checkbox"/> ECHO	<input type="checkbox"/> Hepatitis B Immune Status
<input type="checkbox"/> ECG	<input type="checkbox"/> RPR
<input type="checkbox"/> Bone Age	<input type="checkbox"/> Varicella Zoster
<input type="checkbox"/> Renal Osteodystrophy	<input type="checkbox"/> ABO #2 TCH
<input type="checkbox"/> US ABD/pelvic or CT angiogram (check with surgery)	<input type="checkbox"/> Quantiferon / TSpot
<u>Labs Blood</u>	<u>Labs Urine</u>
<input type="checkbox"/> ABO #1 to TCH	<input type="checkbox"/> Urinalysis with Micro
<input type="checkbox"/> Tissue Typing	<input type="checkbox"/> Urine Culture
<input type="checkbox"/> PRA- 7 ml red top x 1	<input type="checkbox"/> 24 hr Urine for protein and creatinine
<input type="checkbox"/> HLA- 7 ml green Na heparin x 3	
<input type="checkbox"/> ABO #2- 3 ml purple EDTA x 1	
<input type="checkbox"/> CBC	<u>Additional Studies or Comments</u>
<input type="checkbox"/> PT/PTT with INR	_____
<input type="checkbox"/> Comprehensive Metabolic Panel	_____
<input type="checkbox"/> Parathyroid Hormone	

Revised: April 10, 2020 KB

Child Life's Role in Transplant Work Up

- Preparation and education prior to work up starting
 - Initiate conversations about transplant as early as possible
 - Transplant Workbook
- Support during work up related imaging and procedures
 - Voiding Cystourethrogram (VCUG)
- Interview patient and family as part of the multidisciplinary team
 - Complete child life transplant evaluation, place in EMR
- Present patient to the Medical Review Board

Transplant Admission

Depending on the transplant a patient is receiving (living donor or deceased donor) the patient and family will have different amounts of times to prepare.

- Living Donor
 - Scheduled ahead of time, patient and family aware of transplant date
- Deceased Donor
 - Patient and family are called in by the transplant coordinator, and must be available to come into the hospital quickly
 - Challenges may include coordinating dialysis needs, NPO status, and family support during sudden transplant admission

Child Life's Role in Transplant Admission

- Visit patient and family upon arrival (if possible), review transplant education, provide support
- Accompany patient to the OR
 - Child life meets patient and family in OR holding to provide support and distraction, and accompanies patient back to OR, remaining with the patient until they are sedated
- Follow up with patient's family once patient is sedated

Transplant Hospitalization

- Typical hospital course is approximately 2 weeks
 - 2-3 days in ICU
 - Transition to non-ICU floor when appropriate
- What are we looking for?
 - Creatinine
 - Urine Output
 - Pain
- Post-Transplant Life
 - Patient will be NPO during initial days post transplant, with a slowly advanced diet
 - If previously on dialysis, patient's fluid restriction will now change to a fluid minimum
 - Dialysis may still be required for some patients during initial days post-transplant
 - Initiation of transplant medication, including immunosuppressants

Transplant Complications

- Acute Tubular Necrosis (ATN)
- Delayed Graft Function
- Rejection

Child Life's Role in Transplant Hospitalization

- Attend daily transplant rounds
- Follow and support patient throughout hospitalization
 - Procedural support, education, distraction, normalization, coping support
- Family support
 - Provide support to caregivers siblings (if needed)
- Transition to renal transplant team

Psychosocial Challenges of Transplant

- Preemptive Transplant
- Dialysis Patient

Challenges for a preemptive transplant patient

- May be less familiar with the hospital and medical team
 - Have less experience with
 - Procedures
 - Hospitalization
 - Medication

Challenges for a dialysis patient

- Changes in medication
- Transition from a fluid restriction to a fluid minimum
- Delayed graft function requiring dialysis
- Leaving the dialysis unit

Child Life's Role Within the Multidisciplinary Team

- Participate in transplant work up and MRB
- Attend daily transplant rounds
- Collaborate with entire team to provide support to the patient and family

Techniques, Tools, and Resources

- Transplant Workbook
- Patient Education
- Medical Play
- Websites

The Forgotten Child: Supporting Siblings

Amanda Porter, MS, CCLS



Objectives

1. The participants will gain understanding on how to best support the healthy child during the patient's journey.
2. Participants will be able to describe the steps to creating their own sibling group.

Question

How many of you have spent
dedicated 1:1 time with a
sibling?

Background

- End stage renal disease (ESRD) has both a positive and negative relationship on the family unit as a whole; specifically the sibling of the patient reacting with behavioral outbursts (Batte, Watson, & Amess, 2005).
- All healthy children are worried about their siblings, but just over 50% are willing to share their feelings (Batte, Watson, & Amess, 2005).
- “There are immediate and long-term emotional, behavioral, physical, and psychosocial effects of having a sibling with a childhood illness.” (Fanos, et. al, 2005; Fleary & Heffer, 2013)
 - Psychosocial issues include: resentment, anger, anxiety, depression, jealousy, and guilt. (Fanos, et. al, 2005; Fleary & Heffer, 2013)

Background cont.

- Support groups help with adjustment to the new normal (Vatne & Zahl, 2017)
- The sibling voice is often overlooked. (Deavin, et. al, 2018)
- Parental silence is common but can be detrimental to the health child. (Deavin, et al, 2018)
- Increased growth in maturity and adult skills due to less parental interaction and communication (Deavin, et. al, 2018).
- Siblings shared that they would benefit from having information regarding the ill child's diagnosis early on (Deavin, et. al, 2018)
- Self-sufficiency leads parents to believe that the healthy child is thriving--which is why the healthy child is often overlooked (Deavin et. al, 2018)

Child Life Specialist Role

- Fostering Positive Communication
- Psychosocial Assessment
- Routine
- Education & Preparation
- Therapeutic Interventions
- Sibling Support Group
- Multidisciplinary Team Approach

(Batte, Watson, & Amess, 2005).

Psychosocial Assessment

- Emotional
- Instrumental
- Informational
- Appraisal

Murray, 2002

Routine

- Maintaining Routine
- Normalizing New Routines
- Change in Role
- “Sibling Self-Sustainability”



Education & Preparation

- Education
- Health Care Play
 - Hemodialysis
 - Connection
 - Dressing Change
 - Peritoneal Dialysis
 - Connection
 - Dressing Change
- Positive Outcomes

Therapeutic Interventions

- 1:1 time with the sibling
- Improved relationship with sibling
- Coping Strategies
- Champion Board



Sibling Support Group

- Opportunity (Batte, Watson & Amess, 2005; Joosten, Stam, Scholten & Grootenhuis, 2019).
- Quality of Life
- Age Range (Joosten, Stam, Scholten & Grootenhuis, 2019).
- List of Topics
- Challenges

Sibling Support Group Proposal

Nephrology Sibling Group Proposal

Name of proposer: Amanda Porter, MS CCLS

Location: Dialysis Unit

Subject of the proposed publication (working title)

The positive influence of a sibling group on patients siblings' who are undergoing dialysis treatments or have received a kidney transplant.

Main objectives

- Age: 5 years to 18 years
- Meetings: During Family Meeting
- Length of Time: 60-90 minutes
- List of Topics
 - Getting to Know Each Other
 - All About Me (Story Rocks)
 - Understanding Kidney Function/Disease
 - Coping Tools (Worry Box; Relaxations Techniques)
 - Discussing Emotions

End stage renal disease has both a positive and negative relationship on the family unit as a whole; specifically the sibling of the patient reacting with behavioral outbursts (Batte, Watson, & Amess, 2005). The positive outcome in relation to siblings is their increased ability to empathize with their sibling with what is going on. When siblings are provided the opportunity to converse with those who are experiencing similar circumstances, it provides them the ability to express emotions as well as gain support and encouragement (Batte, Watson & Amess, 2005). According to Batte, Watson & Amess (2005) majority of siblings are not comfortable sharing with their parents/ill sibling the feelings they experience regarding their siblings' illness. Providing them with the opportunity to have this could create better quality of life as well as overall improved relationship for the patient/sibling and family unit as a whole. Creating an outlet for siblings would align with Children's Mercy's mindset on the family centered care approach.

Additional Comments/Questions

- Importance
 - Provide siblings the opportunity to have a time that is all about them.
 - Allow them to converse with other individuals who are experiencing what they are (siblings who are in kidney failure; have had a transplant).
- Long-Term Affects
 - Increased quality of life
 - Overall, improved relationship between patient and sibling.

References

Batte, S., Watson, A. R., & Amess, K. (2005). The effects of chronic renal failure on siblings. *Pediatric Nephrology*, 21(2), 246-250. doi:10.1007/s00467-005-2064-9

Multidisciplinary Team Approach

Introduce them to the different members of the health care team to help them know they are part of the process.



The Parent Perspective

- 4 Year Old Sibling
 - “I had so much pain coming in my heart when I could only see baby J every 151 weeks. I was so happy to see him and play with him and make him laugh.” -4 year old sibling
- Sibling Visits During The Pandemic
 - “Having the boys apart ripped my heart to pieces. I hated having to decide each morning who I wanted to see first and how I wanted to spend my minutes with them. The sibling visits put wind back in my sails. I was always so overcome with joy and relief when I could hold both boys in my arms at the same time and kiss their faces.” –Mother
- Therapy Bear
 - It was a useful tool for me and Mitch and to teach Everett about all of baby J’s devices and why it was important to play gently with him. E loved Perry the bear and got a lot of comfort from him. The first night Perry was at our house, E held him tight and told him that he would keep him safe so that Perry would not be afraid. I think it made him feel a little more in control of our situation.



The Sibling Perspective

“When my mom told me that my brother’s kidneys needed help, I was scared and really sad. My mom told me I would meet someone at the hospital that teaches kids about how their kidneys work and when they aren’t doing their job.

Miss Amanda taught me about the job of the kidney. She used glitter and food coloring to teach me about how kidneys work and how my brother’s nurses would help his body since his kidneys weren’t doing their job.

Learning about kidneys and dialysis helped me not be as scared and sad anymore. Thank you, Miss Amanda”

References

Questions

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Child Life & Dialysis Support

Education, interventions, activities, and more!



JOHNS HOPKINS
CHILDREN'S CENTER

Objectives

- The participants will gain a better understanding on how to support children who receive dialysis treatment
- The participants will receive tools and ideas on how to support children prior to, during, and after needing dialysis

ACLP Domain: Intervention

Supporting the transition to dialysis

- Initial consult
- Diagnostic education
- Hemodialysis vs. Peritoneal dialysis
- Preparation & Education
 - Dialysis clinic prep book & welcome packet
 - [Dialysis clinic video](#)
 - Meeting peer dialysis patients

Dialysis Welcome Packet

- Dialysis clinic preparation book (patient and sibling)
- Caregiver Burnout and Self Care
- Being Your Child's Advocate
- Supporting and Empowering Your Child
- Mindfulness for Parents
- Team face sheet

Common Stressors - HD

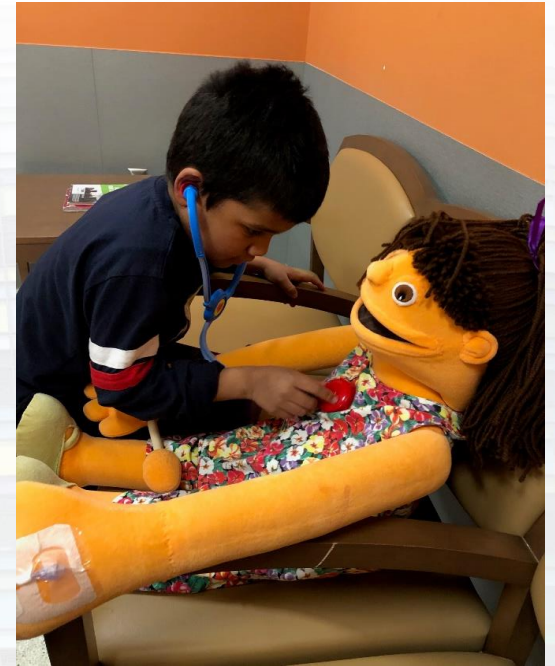
- Preschool/School Age

- Catheter dressing changes
- Staying in the chair for duration of treatment
- Feeling symptomatic and getting scared
- Getting bored and wanting to come off early
- Diet, fluid, medication, routine

- Interventions

- Patient puppet & medical play, incentive charts
- If medically safe, playing on a floor mat
- Symptom cards (ie. Picture of head hurting)
- Activity cards (Today I Am Going To...)
- Schedule

Common Struggle Interventions



3/7/2021

Common Stressors - HD

- Adolescents
 - Body image (fistula vs. catheter)
 - Change to routine & loss of independence
 - Fluid management
 - Guilt/feeling ashamed
 - Engaging in medical plan of care
 - Engaging in dialysis clinic activities
 - **Adherence to medication, fluid, diet, treatment time**

Common Stressors PD

Across the ages



- Extensive training
- PD supplies in home
- Daily routine
- Parent or medical provider
- Vacations
- Family dynamics
- Monthly visits
- Allow for breaks for play
- Include the child in choosing space & routine
- Behavioral psychology for families
- Coping plan for monthly visits

Therapeutic Activities

- Rapport building (all about me, question Jenga)
- Special Events (graduations, proms, holidays, guests)
- Beads of Courage Program
- Pet Therapy
- Nutrition Trivia Game
- [Dialysis Newsletter](#)
- Artist in Residence (music & art)

Therapeutic Activities in Pics

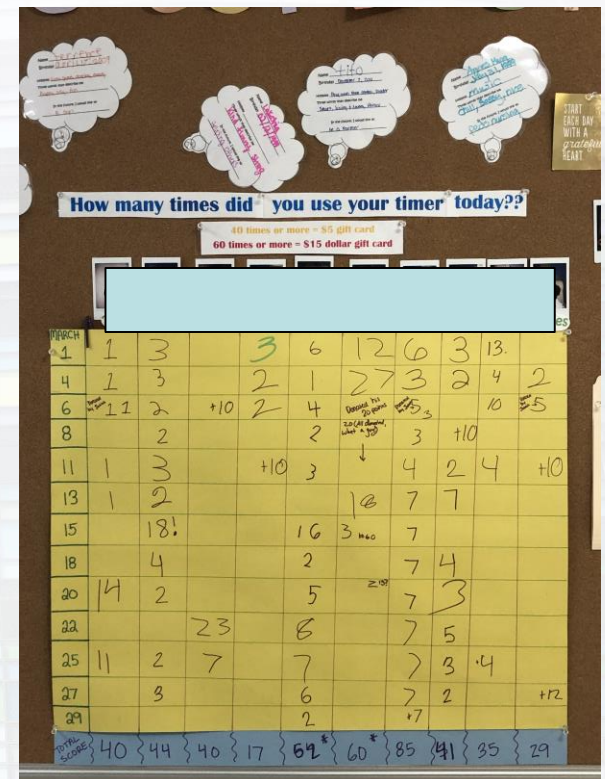


3/7/2021

10

Patient Engagement

- Important Terminology
- Timing Competition (SCOPE)
- Transition Program (SCOPE)
- Unit Transition Program



Unit Transition Program

Topics:

- Managing social relationships
- Fluid (summer months)
- Medication adherence
- Transplant education
- Treatment expectations/diagnosis education
- Mind & Body Connection
- SMART goals
- Nutrition post-transplant
- Nutrition on dialysis
- School & Work
- Communication



FOODY FRIDAYS!

This Nutrition November we are focused on learning about a dialysis friendly diet!

AFTER COMPLETING EACH FOODY FRIDAY

YOU CAN PICK A PRIZE FROM THE TREASURE BOX



Friday, November 6th: We are going to play Nutrition Jeopardy and you will have a chance to win a prize! This game will help us to learn more about fluids, potassium, and phosphorus.

Friday, November 13th: Get ready for a fun Foody Friday snack demonstration with Sami! You can make the treats in clinic or take a baggie with you to make at home.

Friday, November 20th: Sami will be going through a food resources list with you that you will be able to keep and take home.

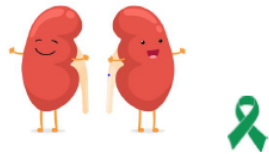
Friday, November 27th: Since it's a bit hard to have a potluck right now, we will be having a clinic picture potluck! Sami will explain all the details to you!

Congratulations! You have completed your Foody Fridays Month!

Transplant Time!

- Transition to Transplant Unit Modules
- Preparation (patient puppet & review of materials)
- Transplant Certificate
- All About Me
- Happy Kidney Transplant Book
- Supporting remaining dialysis patients

Transplant Education



JAZZY JANUARY!

This Jazzy January we are focused on learning about **kidney transplants**!

AFTER COMPLETING AN ACTIVITY EACH WEEK

YOU CAN PICK A PRIZE FROM THE TREASURE BOX



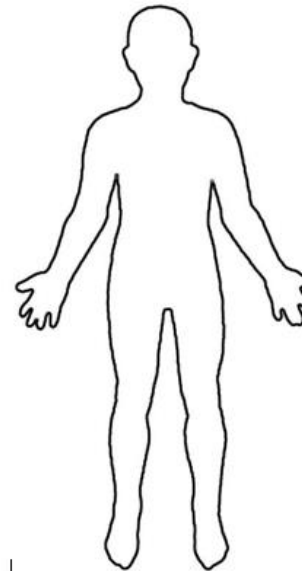
Friday, January 8th: How do you prepare for a transplant? Fill in the blanks to learn about the steps you need to complete to be eligible for the transplant list!

Friday, January 15th: What is a kidney transplant? Watch a video to learn about kidney transplants and talk about it with Nilu!

Friday, January 22nd: What can you expect after your transplant while you're in the hospital? Do a fun art activity to learn more!

Friday, January 29th: What can you expect once you go home? Make some notes in your transplant journal about what is important to remember that you can keep and review when it is time.

Congratulations! You have completed your Jazzy January Transplant Month!



IV – Typically, you will need 2 for as long as you are in the hospital. IV's are small straws that give your body fluids and medicine.



Foley catheter – Remember that your kidney helps to remove fluid and toxins from your body through your pee. The catheter helps your body to pee more easily after surgery. You will typically need it for at least 5 days, but sometimes needs to stay in longer.



JP drain – After surgery your body has extra stuff in it that does not need to be there. The drain helps that stuff to come out so that it does not stay in your body. It will be removed in clinic after you notice that there is no more stuff coming out. This usually takes about 2 weeks.



Staples – Sometimes the surgeon uses staples, which are metal band aids, to close the area where they put in your new kidney. Staples stay in for about 4 weeks before they are removed in clinic.

Questions?

Contact Info

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A Day in the Life of A Nephrology Child life Specialist

March 7, 2021 Judith S. Ross CCLS,CEIM Child life and Integrative Care Services

Objectives

- To provide an overview about the role of a Child life Specialist on a Renal/Dialysis Unit.
- To gain a better understanding about the pathology and treatment of children with kidney disease.
- To learn about how to prepare, support and help children and their families cope with the hospital experience.
- Listening to what our patients are telling us.
- To think outside the box! Hear about innovative programming and therapeutic activities to provide normalization, education, and socialization.



The Day in the Life of a Child Life Specialist

- Picture of Power of One Award with J Ross image



Children's National®

Telling it like it is....

A Renal patients story



Kidneys, kidneys, kidneys...

Main Functions of the Kidney

- 1. Controls Blood Pressure
- 2. Creation of Red Blood Cells
- 3. Removal of Fluid
- 4. Keeps Bones Healthy

[Will add Picture of a kidney]



What is Kidney Disease in Children?

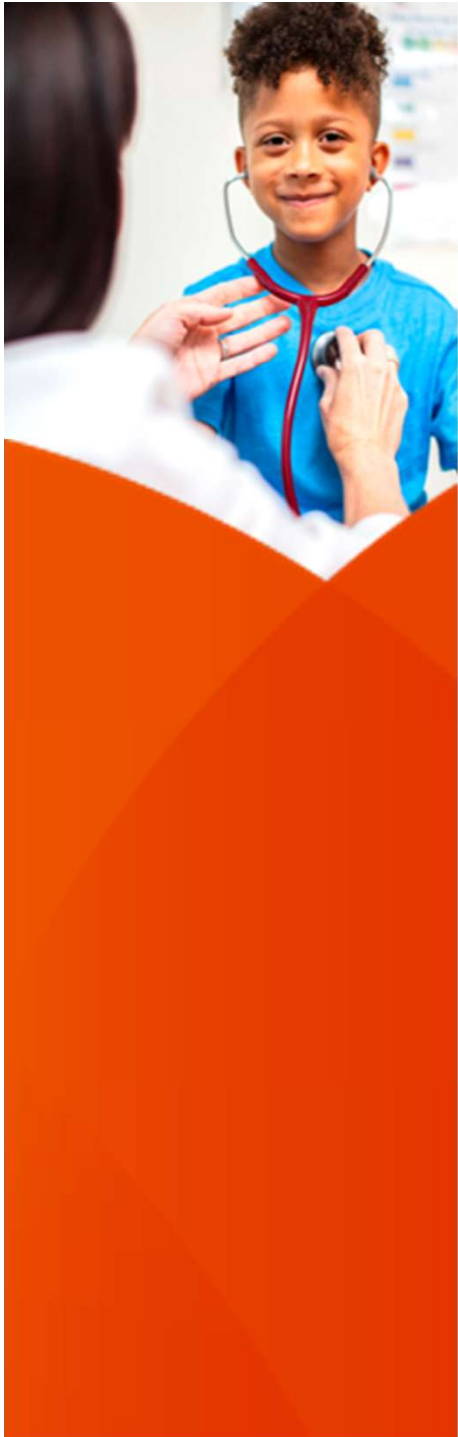
Short Term or Permanent Damage?

Acute kidney disease: Short Term

- Starts suddenly
- In some cases may be reversed
- Kidneys can work normal again

Chronic Kidney Disease: Permanent Damage

- Gets worse over at least 3 months
- Can lead to permanent kidney failure
- Dialysis



What Causes Kidney Disease in Children?

- ✓ Birth defects
- ✓ Hereditary diseases
- ✓ Nephrotic Syndrome
- ✓ Trauma
- ✓ Infection
- ✓ Blocked Urinary tract / reflux
- ✓ Taking incompatible medication
- ✓ Systemic diseases



Diagnosis

- Nephrotic Syndrome- most common in children
- Focal Segmental Glomerulosclerosis (FSGS)
- Polycystic Kidney Disease- genetic- numerous cysts in kidney
- Hemolytic-uremic- syndrome (HUS)- destruction of the small functional structures and vessels inside the kidney
- Systemic Lupus Erythematosus
- ESRD- End Stage Renal Disease- leads to Dialysis



Dialysis

- Peritoneal Dialysis- Home dialysis- Daily- uses the lining of the abdomen to filter the blood.
- Hemo Dialysis – on going dialysis (3- 5 times/week) cleans the blood by cycling through a machine that removes the toxins and wastes. – 2 access
- CRRT- continuous dialysis



Dialysis

- [Picture of patient on machine]
- [Story and picture about being on dialysis]



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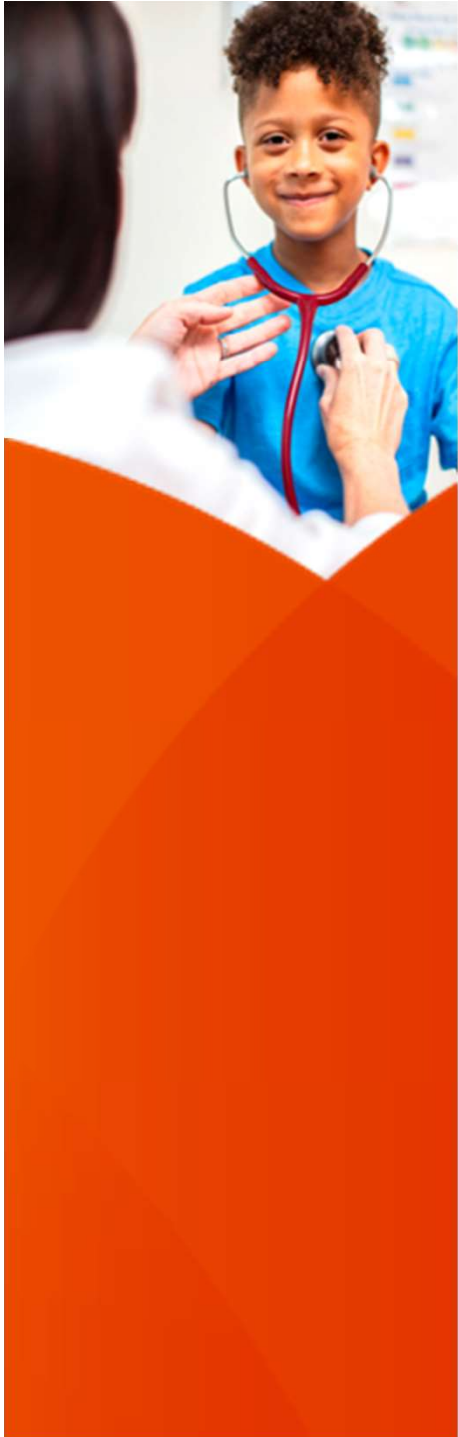
The Role of the Child life Specialist

It Takes a Team to do the work



[Will insert CL meme]

[will insert pictures of typical day]



The Team

Collaborate with a multidisciplinary team:

- Nephrologists
- Social Work
- Psychologist
- Art Therapist
- Dietician
- Dialysis manager, nurse practitioner, nurses and techs
- Kidney Transplant Coordinator
- **The patient and family** ★

Welcome to my world.

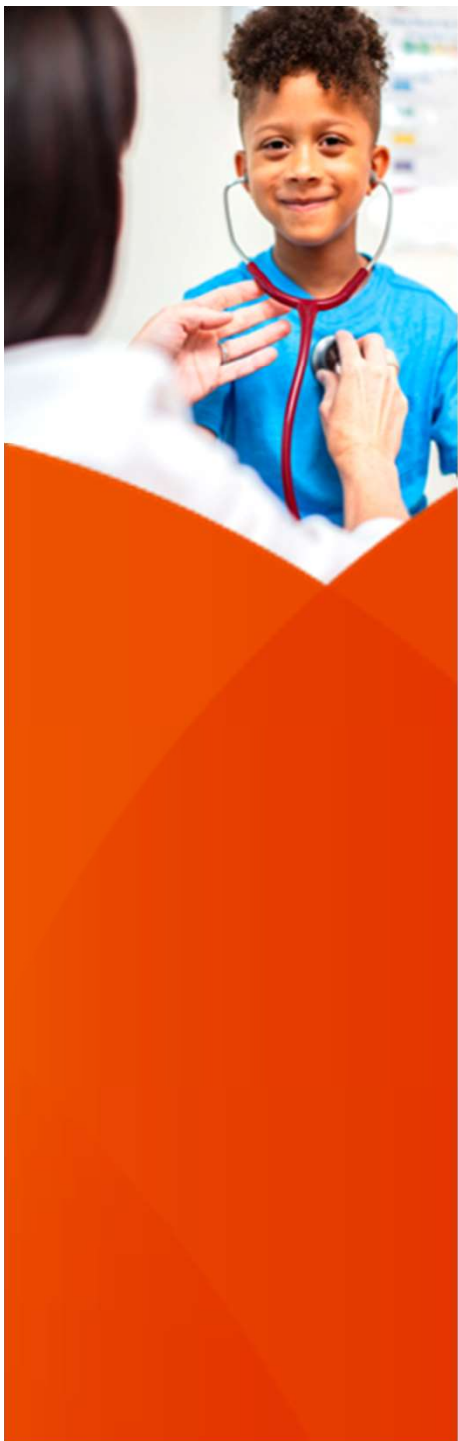
-Inpatient and Outpatient Units
Ages infants to young adults
Split time b/t HKU and Dialysis
Wide range of health issues

[will insert Picture of me w pt.]



A 'Typical' Day of a CLS

- ✓ **Get report** – From nurses, Cerner, Rounds w/ team, Dialysis rounds w/ parent (Zoom) referrals, other staff
- ✓ **Assessment-** From background info; medical status; developmental age; potential stressors; schedule for procedures/tests
- ✓ **Plan-** Who/what needs immediate attention?
- ✓ **Interventions- The Game Plan** Preparation, health care play, procedural support, education, coping support; normalization. Family and sibling support. (if needed)
- ✓ **Evaluation:** Charting; follow up



CLS wear many hats

- [will insert pictures of CLS's]

Procedures and Diagnostic Tests

- ❖ **Biopsies**- assisting w/dx. Kidney disease
- ❖ **Renal Scans/ Ultra Sound**
- ❖ **Surgeries**- nephrectomies, HD and PD catheters, transplants
- ❖ **Infusions** – IVIG, plasmapheresis
- ❖ **Dialysis**- Port access, Fistula cannulation, dressing changes, IV placements
- ❖ **Transplant**- plan, support during and after

What our patients tell us:

[will provide story title with this slide]

Coping with kidney disease

Body Image

- May grow at a slower rate than their peers
- Having a fistula or catheter
- Scars from surgeries and transplant
- May experience depression and anger- why me?
- Self- esteem and negative self image
- Peer relationships- missing out socially, diet restrictions,

Activities that Educate

- Welcome to Dialysis book
- Cook Book w/ recipes from families
- Bulletin board
- Games – BINGO binder, sodium, fluid, bones

[will insert pictures to illustrate]

Activities that Educate

- Guess amount of fluid using different bottles/containers
- Dr. Bear bucks incentive plans
- Treasure Bead program
- Other Activities

[will insert pictures to illustrate]

School: Reuben's Story

Family issues

- Dealing with shock
- Fear about their child suffering or dying
- Guilt – Is it my fault?
- Sadness/ depression
- Anger – disrupting family life
- Over protectiveness
- Having kidney disease affects the whole family

Family support

- Develop an authentic relationship with the child and family.
- The relationship can be decades long.
- You will help with the happy moments and sad ones.
- You will bring some normalcy into their lives, celebrating birthdays, holidays and important milestones.

Celebrate with Creativity:

Renal Teen Prom – Dancing Under the Stars

- CNH and RSN collaborated to bring the first ever East Coast Renal Teen Prom
- Prom Dress give a way – 40 dresses given to patients that wore them at the prom
- Attended by patients age 14-24 from DC, Virginia, Maryland and Boston.

[will insert pictures]

Celebrate with Creativity:

Renal Teen Prom – Dancing Under the Stars

- Students from DeMatha and Seaton High School were also educated about kidney disease prior to the prom and attended the prom.
- The prom was complete with a DJ, a performance by a hip hop group, beauty makeovers, photo's and a limo ride.
- Fox News reported the event

[will insert pictures]

Renal Teen Prom

[more pictures Will be good]

Gowns with an Attitude

- ❖ A Fashion show featuring couture hospital gowns designed by Children's dialysis patients.
- ❖ Patients designed their unique gowns and talked about why they designed their gown the way they did.
- ❖ Many of the teen patients haven't told their friends about their condition
- ❖ Did it to raise awareness about the need for organ donation?

Gowns with an Attitude

- ❖ Collaborated with Fashion show consultant and model, Stylists, seamstress and DJ from the community.
- ❖ Street clothes for dialysis patients donated by Madness.
- ❖ Designers' had hair and make-up done by Ma'Passion Hair design.
- ❖ Collaboration of Child life and Art therapy Department
- ❖ Gowns w/ an Attitude displayed in CH atrium

Gowns with an Attitude

Pictures

The Healing Project Quilt

A multi-generational project

- ❖ Dialysis patients each were given a square of muslin to create a design.
- ❖ The squares were made into a quilt by grandparents that were raising their grandchildren who had a medical condition and are CNH patients.
- ❖ A premiere party was held to unveil the finished quilt.
- ❖ The quilt is displayed on the wall at CH dialysis Unit.

[insert The Healing Project pictures of quilt]

Treasure Beads

“For each landmark sailed past a patient will receive a bead souvenir to add to their treasure strand. As the knots march onward patients’ treasure strands will become a trove of colorful memories symbolizing their strength and resilience.”

Picture of Treasure Bead Poster

Created by Alli Marler – Dialysis Child life Intern

Theme Parties

The dialysis patients were bored so 'theme parties' were created by Child life in collaboration with the dialysis nurses.

- ❖ Crazy Hair Day
- ❖ Beach Week
- ❖ Hooray for Hollywood
- ❖ Heroes party
- ❖ Design a mask

Theme Parties

The dialysis patients were bored so 'theme parties' were created by Child life in collaboration with the dialysis nurses.

❖ Crazy Hair Day [will insert picture]

❖ Beach Week [will insert picture]

Theme Parties

The dialysis patients were bored so 'theme parties' were created by Child life in collaboration with the dialysis nurses.

- ❖ Hooray for Hollywood
- ❖ Heroes party
- ❖ Design a mask

[will insert pictures]

Theme Parties

The dialysis patients were bored so 'theme parties' were created by Child life in collaboration with the dialysis nurses.

❖ Design a mask

[will insert pictures]

Theme Parties

Pictures

Book of Inspiration

Transplant stories written by patients, caregivers and donors about having a kidney transplant.
Stories are read as an inspiration to patients that are getting ready for a transplant.

[Excerpts & Pictures to be inserted]



Children's National®

Video of Austin

Austin Lee's video about Why he wants to be a CLS

*“Quote about being a Child life
Specialist”*







Resources: Websites

- I hate dialysis: www.ihatedialysis.com
- Kidney Foundation: www.kidney.org

(etc.)



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Thank You!



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