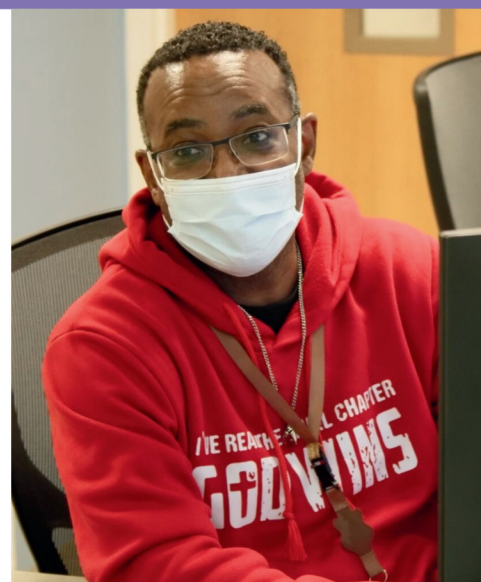


The Heart of What We Do:

CONNECTION THROUGH EMPATHY



Patient & Family Experience



**St. Jude Children's
Research Hospital**
Finding cures. Saving children.

Dear St. Jude,

My name is Kady Shell, and my Hattie Lucille was brought to St. Jude in the middle of the night from another pediatric ICU on September 3, 2021. She had already been hospitalized for almost 5 weeks.

At that time, the medical teams at both hospitals were still unsure of her diagnosis, but the prognosis of her survival was not good. At her time of admission, Hattie was on very high ventilator settings, her spleen and liver were substantially enlarged, she could not maintain any of her blood or platelet counts, and within 4 hours of our arrival at St. Jude, she suffered a pulmonary hemorrhage.

After a few gut wrenching days at St. Jude, the team determined that Hattie was suffering from HLH which was being triggered by Anaplastic Large Cell Lymphoma/Leukemia....and that is the short story.

I often describe Hattie as a unicorn because even St. Jude had not seen her combination of illnesses in one person – ever. What I don't get to explain as often is how our entire experience was very atypical of most St. Jude families:

- We were admitted via ambulance entry in the middle of covid protocols at 3AM – by a team of nurses.
- We lived in ICU room 1 for almost a month – with **OUR** care team.
- When Hattie was finally transferred out of ICU and eventually transitioned to a Non Protocol Treatment Plan, we were admitted for EVERY cycle for her medicines to be administered by **OUR** nurses.
- In a year of treatment, we spent approximately 90 days inpatient. That translates to 2,160 hours primarily spent – with **OUR** care team.
- In 2022, we spent almost 100 days at outpatient appointments. Every one of those days started and ended – with **OUR** care team.

I say **OUR** care team because not only did this team of men and women work constantly to save my girl's life, they also went above and beyond to care for and support me, my husband, and Hattie's big sister, Hazel.

As I write this, Hattie is officially 571 days into complete remission. That equates to about a year and a half. For my husband and me, those are 571 days that we would not have gotten to spend with our Hattie if it wasn't for people like you and **OUR** care team who helped carry us through the hardest experience of our lives.

So when the shifts are long, the kids are cranky, and nothing seems to be going the way it is supposed to, please know you are the lifeblood that keep us going when we can't take another thing. You are the support system that we trust to care for our children when we have no idea what is going to happen next.

The things you remember about our children makes them feel special; it makes their siblings feel included and less forgotten during the throws of having a sick brother or sister, and it makes St. Jude a place where we are family instead of strangers.

The trust you build and the encouragement you give our children as they endure “pokes” and dressing changes and pain and nausea and line flushes and IV’s and every other terrible part of cancer treatment sticks with them for the rest of their lives.

These kids can do hard stuff, and you, as care team members, are the people who help them believe that about themselves.

Thank you for the work you do. Thank you for the sacrifices you make to help families like mine. Thank you for being **OUR** care team and the best team I’ve ever had the privilege to be a part of. You are so loved and appreciated – forever.

Kady Shell



Hazel, Wes, Hattie, and Kady Shell

Healthcare can be
defined as **human
beings taking
care of human
beings.**



Jason Wolf
President and CEO
The Beryl Institute



Where are we?



Where could we be?

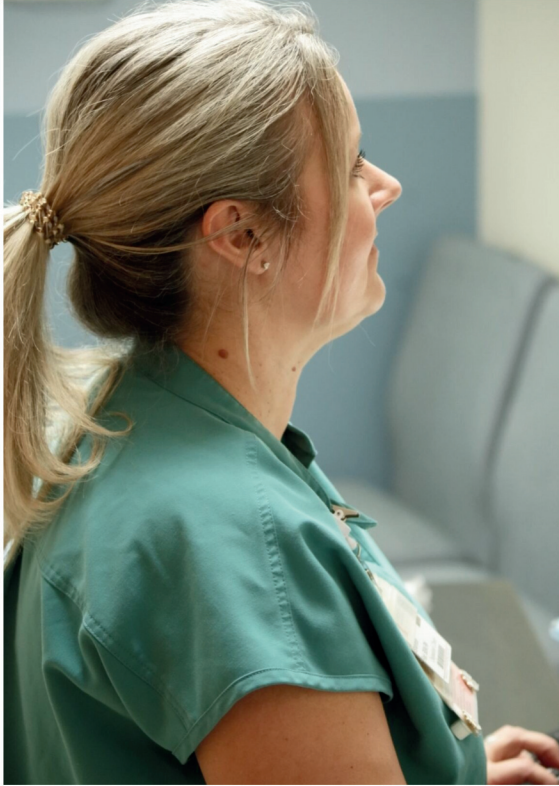


Creating the good stuff.



TABLE OF CONTENTS

WHERE ARE WE?



What do our families teach us?

Through Press Ganey surveys, families tell us that they are consistently having to wait to be seen. At times, they do not understand why they are waiting, or why they are waiting for long periods of time.

Leadership is focused on improving customer service by decreasing patient wait times (without compromising safety or experience). Wait times can be viewed through two lenses: actual wait times and the perception around wait times.

This resource will be focused on the **perception** of wait times and how we as St. Jude staff can **support** our families while they are waiting.

In full transparency, our current Press Ganey satisfaction scores are very good, but can we strive to be better?

The family's perception about wait time is often **more important** than the actual wait time. For that reason, it is important to focus on what is within our span of influence related to wait times:

- **The way we connect**
- **The way we communicate**

Learning from others

In 2012, a Texas airport was struggling with customer satisfaction in wait times for baggage claim. To improve, the airport added 8 baggage handlers and successfully reduced wait times to less than 8 minutes. This did not improve complaints, nevertheless.

When the airport looked closer, they realized passengers were spending about 88% of their time waiting at the baggage claim area. So they tried something new.

Planes were rerouted to arrival gates further away from baggage claim. This greatly **increased** the time a passenger walked within the airport and thus decreased the time they were spending waiting on their luggage.

Though it seems counterintuitive, satisfaction scores greatly improved.

IS PERCEPTION REALLY THAT IMPORTANT?

How can we apply this in healthcare?

The universal takeaway is **perception matters.**

Also, it may be easier to change perception than you think. A survey by the Advisory Board, a health care research and consulting firm, revealed that resolving perceptions of wait times can have a big impact on satisfaction.

Acknowledging a patient's wait, either by updating them about delays or by apologizing for their wait, can have a **huge impact** on satisfaction.

These are things that are within the span of influence for St. Jude patient-facing staff.

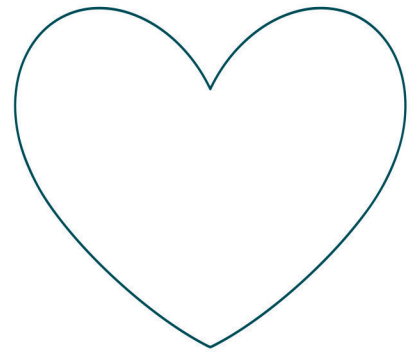
What would eliminate frustrations about wait time?

2014 Advisory Board Survey - 5000 patient responses



Would somewhat or completely eliminate frustration

WHERE COULD WE BE?



Let's think for a moment.

Clinical and technical competence are not optional in healthcare. Why should kindness, caring and compassion be?

In this resource, you will:

- Examine the importance of connecting with patients and families.
- Learn tools to facilitate connection.
- Investigate the power of stories in connection.
- Learn tips on connection and communication with upset patients and families.



THE IMPORTANCE OF CONNECTION

“we are in this together”

Connection is a human process.

Our relationship with the patient is not separate from the medical care we provide. This connection benefits patients, families, and staff.

Connecting with others creates safety, comfort, helps people cope, and promotes healing.

We asked St. Jude patient-facing staff, when do feel like you are making a difference? They told us:

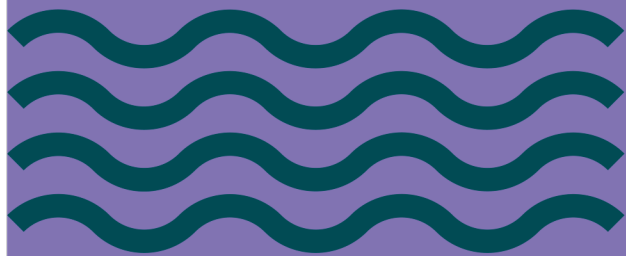
Everyday when patients arrive to the hospital, we are their first point of contact.... we set the tone for their visit. Remembering such things... as the patient's name and other details make the interaction more personal.

I am able to reassure [families] that they are doing a great job taking care of their child. I [take] the time to answer any questions and meet needs.... simple things like helping to change an appointment time to make their day easier.

I have been here for 15 years, parents still come by to tell me thank you for helping them.

Offering a bed to lie down in for a sleepy patient, or giving a mom a listening ear.... sometimes small things make the biggest difference.

The nurse gave us
time and attention
that we have not
seen anywhere else.
It gave us great
confidence in the
system at St. Jude.



Patient comment
Press Ganey
satisfaction survey

THE PATIENT'S POINT OF VIEW

What do our families teach us?

Sometimes, we forget how frightening the hospital setting can be. Things that are routine for staff are **new** and **scary** for our patients and families.

Making patients and families feel safe is one of the most important things we can do. If they think you are rushed, they will feel unsafe.

What do our families tell us?



Connecting

Look at me - not your phone.

Smile when you greet me. I can tell even through your mask.

Listen for understanding. Please don't interrupt or rush me.

Recognize and name my emotions so you can help me deal with what's going on.

Apologize for mistakes and lateness, even if they are not yours to own.

Small acts of kindness mean so much - a warm blanket, asking how my week has been, remembering my birthday.

See me as a person

My illness does not define me.

I am more than just my MRN.

Sit when talking to me, if possible.

Know my name and something personal about me before you begin treating me.

Let me know what you are going to do and what to expect.

Use words I can understand.

Tell me what I need to know - you, after all, are the expert.

"The nurse who drew my blood would not engage in conversation. I was a bit **nervous** with the amount of blood being drawn and hoped she could engage with me as the adult patient."

"He and I **bonded** over music and art, and he and mom had a nice talk about Downtown Memphis... He made my procedure experience very pleasant."

"[They] always taught us what to do in the easiest way possible so we could **understand and remember** instead of in crazy medical jargon!"

PATIENTS AS OUR TEACHERS

Consider this, what will families say about you?

"I sometimes get the impression that the staff have done all of this a thousand times before so it's almost become **automated**. But it's our first and only time, so we need the directions and explanations given to us in a personalized and slow way."

"She and my daughter **connected**. She is a beautiful soul and always puts a huge smile on my daughter's face. We love her for that. She is an awesome ... friend."



CREATING THE GOOD STUFF

How might we create the ideal experience?

Creating the ideal experience for our patients and families includes:

- Staff who can balance **compassion** and **expertise**
- A **focus on the person**, instead of the task

Cultivating a New Mindset

- 01** Recognize that communication is powerful
- 02** Practice and consistency are key
- 03** Consider the backstory
- 04** Connect when it's hard
- 05** Use communication strategies



Communication is powerful



The words we use and how we deliver them matter. We must learn to communicate with all of our senses:

Observe the patient/family reaction, understanding, and response.

Use your **eyes & ears** to determine if your words make sense. Pay attention to what they are understanding rather than what you want to say.

Imagine what the patient/family is going through (life does not stop because a diagnosis exists).

Practice and consistency are key

It is important to **celebrate connection** between caregivers and families through storytelling:

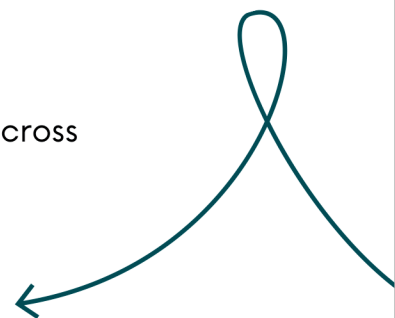
- Tell your co-worker what a great job they did in meeting the needs of a particularly "difficult" patient.
- Begin (or end) the day by talking as a group about what went WELL on your shift.
- Nominate a co-worker for a DAISY award, write an Ovation, submit their name for Living Our Values.

Consider this exercise:

Cross your arms. When they are comfortably crossed, undo them and cross them the other way.



Think, how hard was it to make the change?



Like many other changes, **connecting with intention may feel weird at first, but gets easier with practice.**

Consider the backstory

"Due to brain damage, he has some processing delays, sensory issues, etc. He cannot control his body temp due to hypothalamus damage, so when he needed the blanket removed, they tried to tell him he would be fine - just wait. They didn't tell him before they accessed his IV to inject contrast, which caused him some anxiety. Everybody is entitled to an off day, but I feel like if you are working with children - the patient should never feel like they are talking mean or being impatient."

"My hair started falling out yesterday and it has been hard. I thought I wouldn't be upset over it but it turns out I was wrong. I think it's just finally hitting me that I have a tumor and that my journey is only just beginning. Trying to stay positive and find things to keep me going."

Our kiddo has a trach and requires 24/7 supervision and only my husband and I are qualified to care for him. He has a pulse ox, trach collar and nose tube with continuous feeds... he doesn't sleep soundly and there's always an alarm going off.... During the day our schedule is completely full and by the end our son is completely exhausted and we barely make it to bedtime.

I don't know how we're going to survive much longer without extra help. We are so tired... mentally and physically.

Take a moment to think about a time that you changed your mind about a patient or family member based on hearing their "backstory."



What matters most is that [caregivers] have empathized with me in a way that gives me hope and makes me feel like a human being. Again and again, I have been **touched by the smallest gestures - a squeeze of my hand, a gentle touch, a reassuring word**. In some ways, these quiet acts of humanity have felt more healing than the high-dose radiation and chemotherapy that hold the hope of a cure.






Kenneth Schwartz
Founder
Schwartz Center Rounds

Connecting when it's hard

The ability to empathize with others is evidence of **high emotional intelligence**. Empathy moves us to be more understanding and helps us to be better caregivers, co-workers, and leaders.

The ability to use empathy with others around you - especially those who are not in your same situation - allows you to have more meaningful relationships. Let's look at some examples:

SCENARIO	CONTROLLING HOW WE THINK AND REACT	
	Disconnected - apathetic	Connected - empathic
	I'm going to need an interpreter. Great, this is going to take forever.	Let me go say hello while we are waiting for an interpreter. I cannot imagine going through all of this in a foreign country.
	I hope they don't speak English... I can get in and out.	I know some basic Spanish phrases from using DuoLingo. Hopefully me saying "hola" with a warm smile will give them assurance I care.
	This is my last patient to help before lunch.	There is a 14 year old patient waiting for scan results. He looks more nervous each minute.
	Am I the only one who works in this department?!?	I can make a difference in this person's life today. I want to bring hope and happiness.
	I do not have the mental capacity to deal with this today. She only complains and questions everything I do.	I cannot imagine what it is like to be in their shoes. I know this mom gets anxious when her kid gets chemo. I'll explain the process to her and make sure she is comfortable.
	Someone needs to explain to them why they are wrong.	I'm not sure how to handle this. I'm sure there is something we can do to help. If I can't figure out how to do it, I'll get a CSL to help.

WHAT HAPPENS WHEN IT'S JUST A BAD DAY?

Communicating with an angry patient or family member

Remember, **anger is a secondary emotion** - a "symptom" of something else that is going on. Anger is an attempt to regain control due to feelings of fear, powerlessness, loss, pain, or struggling with coping.

In patient experience, we like to say, **there are no difficult families, they are just difficult situations.** Remember, all of our families are in difficult situations.

We can respond to anger in a number of ways:

- Remain present, listen without defense
- Try to not take the words personally
- Be curious, ask questions to learn where the anger is coming from
- Let the person know they are seen, heard, and maybe even understood
- Name the emotion, "I can see you are really upset....."
- Say "I'm sorry" as a way let them know you understand they feel wronged or ignored

Using a blameless apology

The Einstein Healthcare Network defines a blameless apology as a heartfelt regret that people are suffering without blaming others or yourself. This strategy always includes the words, **"I'm sorry."**

- "I am so sorry this has been so hard for you and your family."
- "I'm sure the last thing you wanted was to spend so much of your day waiting for your child's appointment. I'm sorry."

Of course, we recognize, **the struggle is real!** In today's work environment, technology, tasks, and other demands can lead to fatigue and burnout. Empathizing with patients and families who are suffering will cause you to feel their pain.

We must learn to balance self-care with caring for others, but it is not easy.

“I describe St. Jude as the
‘**unicorn**’ of hospitals.
Dedicated, knowledgeable
staff who are also
exceptionally
compassionate and kind
work here. I feel blessed
that [my son] has had the
best treatment possible
here. Thank you.”



Patient comment
Press Ganey
satisfaction survey

Tools for communication

Remember, actions speak so much louder than words.

Over 90% of our message is interpreted through our non-verbal cues. Stop and think, what message do we show families when we make that first point of contact?

- Smile, make eye contact
- Sit at **eye level** when possible
- Acknowledge the patient and their family
- Have open body posture
- Do not show that you feel rushed
- Silence is okay - stay focused on family
- Listening can, at times, be more important than speaking

Providing WOW service can be the name of our game.

Wow service does not have to be over the top. It can be **simple and standardized**.

Wow service can look like:

- Offering someone a cup of ice if they brought in a soda
- Offering to bring a patient a blanket to keep them comfortable for their long appointment
- Informing families about realistic wait times while telling them about activities happening in the hospital



Did you know?

The Peabody hotel asks guests when they arrive if they've stayed there before. If so, staff say, **"welcome home."**

That greeting can give you the impression of comfort in familiar surroundings.



We can use communication frameworks to make meaningful connections with patients and families.

Communication strategies are great aids to have in your toolbox. Let’s walk through the following models:

- AIDET
- Heart, head, heart



AIDET

A	Acknowledge the patient and family by name	"Good morning, Sam, are you here to check in for your appointment?"
I	Introduce yourself and your role	"I am happy to do that for you. It's my job to make sure you have what you need."
D	Share the duration , or how long this will last	"Hopefully, we will be able to see you soon. Your lab results should be back in about 30 minutes."
E	Explain what is happening	"I am finishing checking your chemo, and we will get started with your pre-meds shortly."
T	Thank the patient and family	"Thank you for letting me take care of you today. Have a great night and try to get some rest."

This model provides a mental checklist for how to communicate with our families. Do we need a guide? Probably not, but it can help us do our job better and give us a way to communicate the same way with each family.

Heart-Head-Heart

The Language of Caring

This model shows us how to balance task-oriented activities with communication that conveys caring and emotional support. Remember, **always lead with your heart.**



Heart Responses

"I am sorry you are in pain."
"I want to make you more comfortable."
"This must be very hard for you."



Head Responses

"Rate your pain."
"I can check back in 45 minutes."
"The doctor says to wait."



All communication we deliver at St. Jude should be patient and family centered. Keeping the following guidelines in mind allows you to build connection and nourish it through meaningful communication:

1

Establish & nurture the relationship

2

Build & keep trust

3

Listening is key

4

Show empathy

5

Treat families as partners

6

Remember: all families are unique

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.[illegible]

23

Notes

[illegible]

