

Partnering with Patients: A Bed's Eye View of PFCC

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Where we're going...



A "Hybrid Patient" Perspective

- Defining PFCC
- The 4 Guiding Principles of PFCC
- The Platinum Rule of PFE



Why the culture change?



- * Pts with more access to information
- * Competitive markets
- * Questions about boundaries and rights

So how do we keep up with
shifting expectations?

How do we improve the patient
experience while attending to so
many other demands?

The Institute for Patient and Family
Centered Care defines Patient/Family
Centered Care (PFCC) as:

*Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. **It redefines the relationships in health care.***



“My organization is working at improving the patient experience by being more patient and family centered but not all of our staff/leaders are on board. What can we do to help them understand the importance of this effort?”

Answer:

Always start with STORY...





Diagnosed
at 6 months
old with the
gift
of cystic
fibrosis

I had a relatively normal childhood



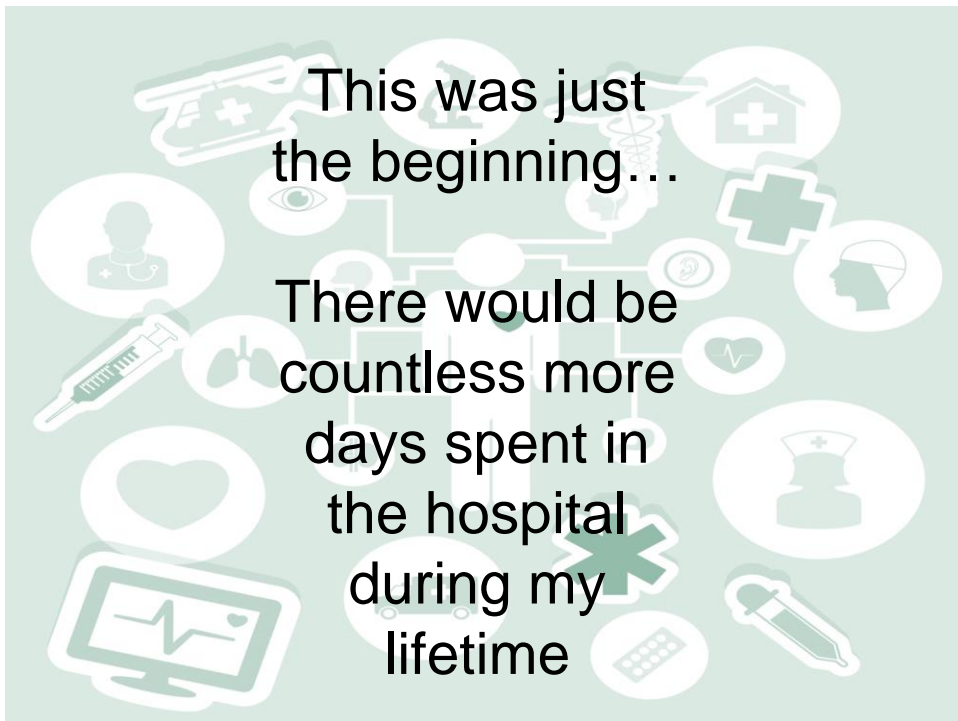
I had my first
hospital stay at
Age 12

I had three weeks
of intravenous
antibiotics and got
my first taste for
the need to be an
advocate



This was just
the beginning...

There would be
countless more
days spent in
the hospital
during my
lifetime



By age 21, I was sick almost all
of the time.

I was attending the North
Carolina School of the Arts and
I just couldn't keep up.

I had to give up my Hollywood
dreams and drop out.

I waited 4 years for my "call"

I was 95 pounds and
my lung function was
25% of capacity



Facing Medical Error

Surgical Error:

“Wet Run” and an apology

Ripple Effect of Reactions:

In the OR

In the Transplant Protocols

In Safety Procedures Hospital Wide

I waited 1 more year for my first
set of donor lungs



Now, due largely to the
surgical error,
I was 87 pounds and
my lung function was
18% of capacity

Patient and Family Centered Care Guiding Principle:

Participation

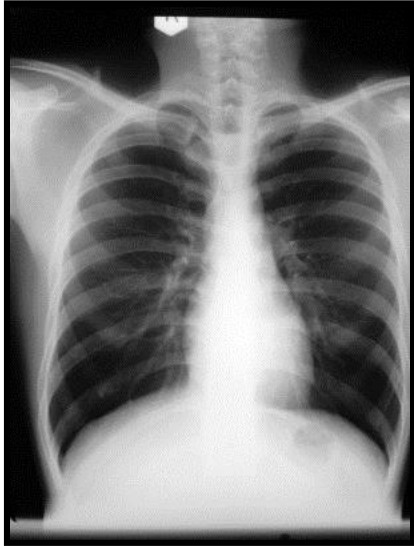


I traveled a winding
road of confusion
and self-doubt.



I didn't know how I
wanted to make my
mark on this world.

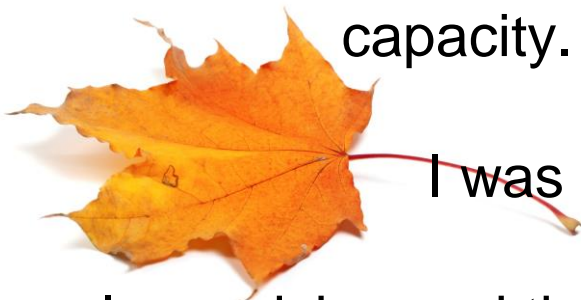
I didn't know how to
live a life with
healthy lungs.



In June of 2002,
my lung function
started to drop.

I was diagnosed
with my second
terminal illness 6
months later.
I had Chronic
Rejection.

Within two years, my lung
function had dropped to 10% of
capacity.



I was 73 pounds.

I was dying and the doctors
gave me 6 more months to live.

I asked my
doctors if I
could have a
second lung
transplant.



They said no.

I reconnected with
the understanding
of my childhood
CF was my
greatest teacher
and I was grateful



I was at peace

Only 4 months after I was listed,
I got “the call”

My fear was overwhelming
Going into the OR, I was looking
for comfort



Patient and Family
Centered Care Guiding
Principle:

Dignity and Respect



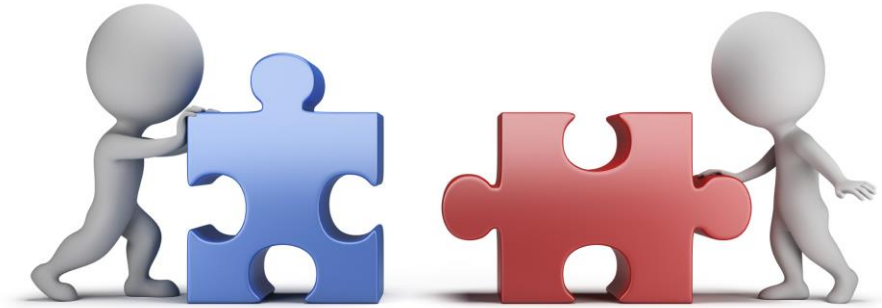
Despite my
team's
concern, the
recovery was
easier than
the first time.

Unlike after the first time, I was
not confused about what to do
with my life.

I felt a strong calling to reach
out to others touched by illness.

I wanted to share what I had
learned...

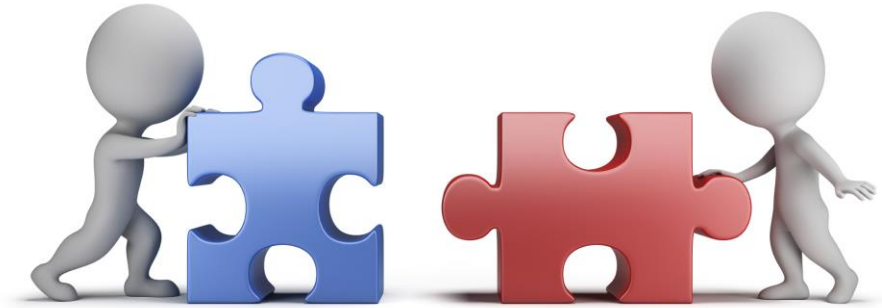
Preaching Partnership!



Patients are so different! Diversity of:

- Experience with healthcare
- Cultural/family/regional background carrying conscious or unconscious beliefs
- Motivation based on illness, prognosis etc
- Support varying from invasive to non-existent
- Socio-economic background shifting focus or worry from health to something else (including health literacy)
- Personality!

Is Partnership Possible?



Partnership is a
process

*Centers around
Customization
of Care*

*Several
issues
addressed*



THE PLATINUM RULE

- Diversity respected
- Fewer missed opportunities
- Improved satisfaction

THE PLATINUM RULE



Not sure how patients and families can best be a part of the team? Just Ask!

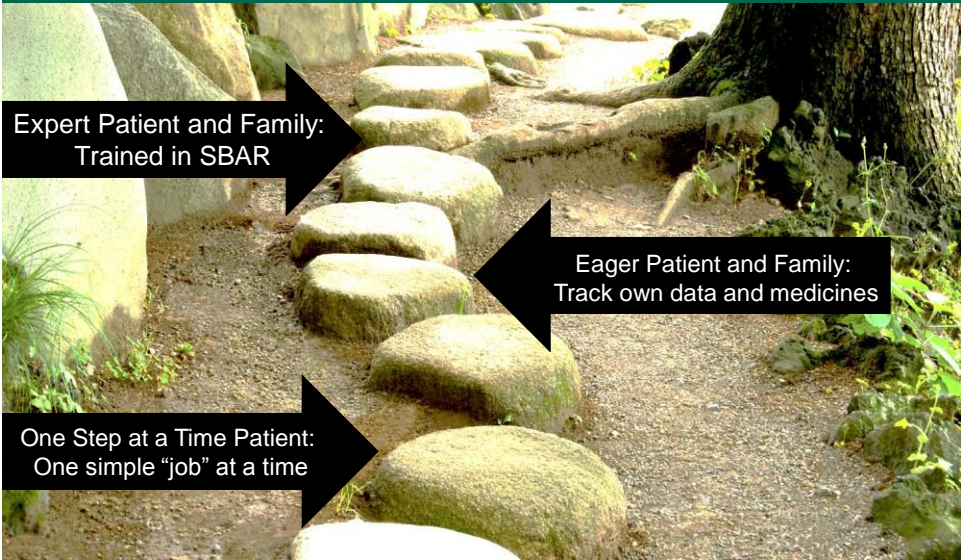
For some questions, that may mean ask your PFAC!

Patient and Family Centered
Care Guiding Principle:



Collaboration

Assess patient/family participation
skills/readiness



Expert Patient and Family:
Trained in SBAR

Eager Patient and Family:
Track own data and medicines

One Step at a Time Patient:
One simple "job" at a time

And sometimes, no matter what, people will be dissatisfied...



It's a Ripple Effect.

Board of Directors/Trustees



Healthcare Administration



Direct Patient Care



Support Staff

Patient-Centered Care
at Every Step

Thank You!

sickgirlspeaks.com

