

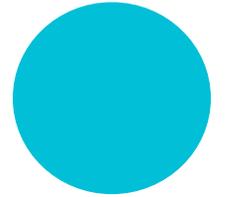
# 8 Lessons Learned During the Transition to Adult Care

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# About Julia

- Medically complex
  - Complex Care
  - Neurology
  - GI
  - Rehab
  - Pulmonology
  - Hematology
  - + More
- Non-mobile, non-verbal
- 27-day ICU stay in February with RSV
- Turned 18 March 31



# Lesson 1 – Start with choosing a health system

- What hospital can best meet her needs?
- Which health system is most closely connected to our children's hospital?
- Which health system is in-network for our insurance?
- Which health system does the rest of our family use for health care?



***PRO TIP: You could choose specialists from different health systems, but give serious consideration to how having doctors in different health systems will impact continuity of care and care coordination.***

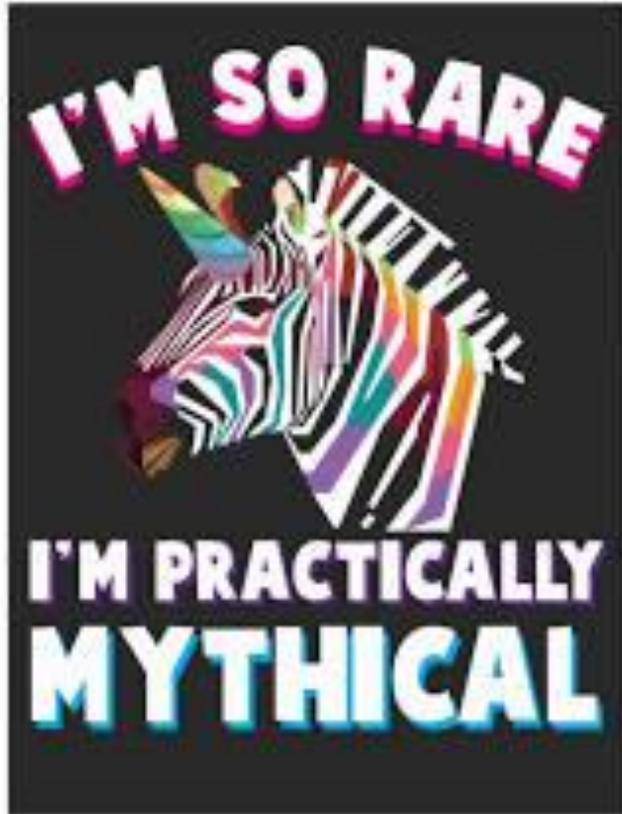
# Lesson 2 – Determine if it's a partial or complete transition

- What age for transition? Is it different for different specialists?
- Would we be sacrificing care quality or specialized knowledge by transitioning certain specialties to an adult provider?
- Do any of her current providers in the children's system also see adult patients? If so, can that provider help serve as a bridge between the pediatric and adult systems?



***PRO TIP: It can be tempting to keep any pediatric specialists that you can, but a partial transition can create different issues, such as during hospitalizations.***

# Lesson 3 – Choose a primary care doctor wisely



- Consider a Med Peds Doctor
- Personality and 'bedside manner'
- Size of the practice, number of doctors on the team

***PRO TIP: It can be really hard to find a primary care doctor who meets your needs AND is accepting new patients. Take your time and don't lose heart.***

# Lesson 4 – Map it out to avoid care gaps

- Overview of care providers and specialists
  - Why our daughter sees them
  - How often we typically have follow-up appointments
  - Which medications each specialist has prescribed
  - Any paperwork/forms needed on a regular basis



***PRO TIP: The goal is not to exactly replicate the pediatric team because adult care is not exactly the same. It's more important to make sure each care need is accounted for, even if it's a different specialist.***

# Mapping Providers from Pediatric to Adult Care

Specialty	Summary	Appointment Frequency	Prescribed Meds	Current Provider	Future Provider	Notes
EXAMPLE Primary Care/ Pediatrician	Local pediatrician, first visit with 'minor' illness	Annual and as needed				
EXAMPLE Complex Care	Doctor, nurse case manager and care coordination assistant who create shared plan of care, help streamline admissions, round with team during inpatient stays, overall care coordination, plan of care every 60 days	Every 6 months				
EXAMPLE Neurology	Managing epilepsy and seizure medications	Every 3-4 months				
EXAMPLE Pulmonology	COPD, frequent respiratory illnesses	Annual				

[Get the template](#)

# Lesson 5 – Get lots of input when choosing adult specialists.

- Other parents, friends, and family
- Primary care doctor
  - Who do they have good relationships with?
- Pediatric specialists
  - They know you and your family, as well as your child's specific care needs
- Encourage the pediatric team to work with the adult specialist
  - Exchange information, not just medical records
- Bonus – have an appointment with both the pediatric and adult specialist at the same time

***PRO TIP: Adult healthcare is not always ready for medically complex kids.  
Building the right team requires patience and advocacy.***

# Lesson 6 –Telehealth can be an opportunity

- Information sharing
- Relationship building
- Strategize
  - Complete transition template
  - Talk about specialists who might be a good fit



***PRO TIP: Spend time preparing for your telehealth appointment. Make a list of questions and/or have a list of goals for the appointment. And, be clear about everyone's next steps.***

# Lesson 7 – Have clear expectations during the transition process

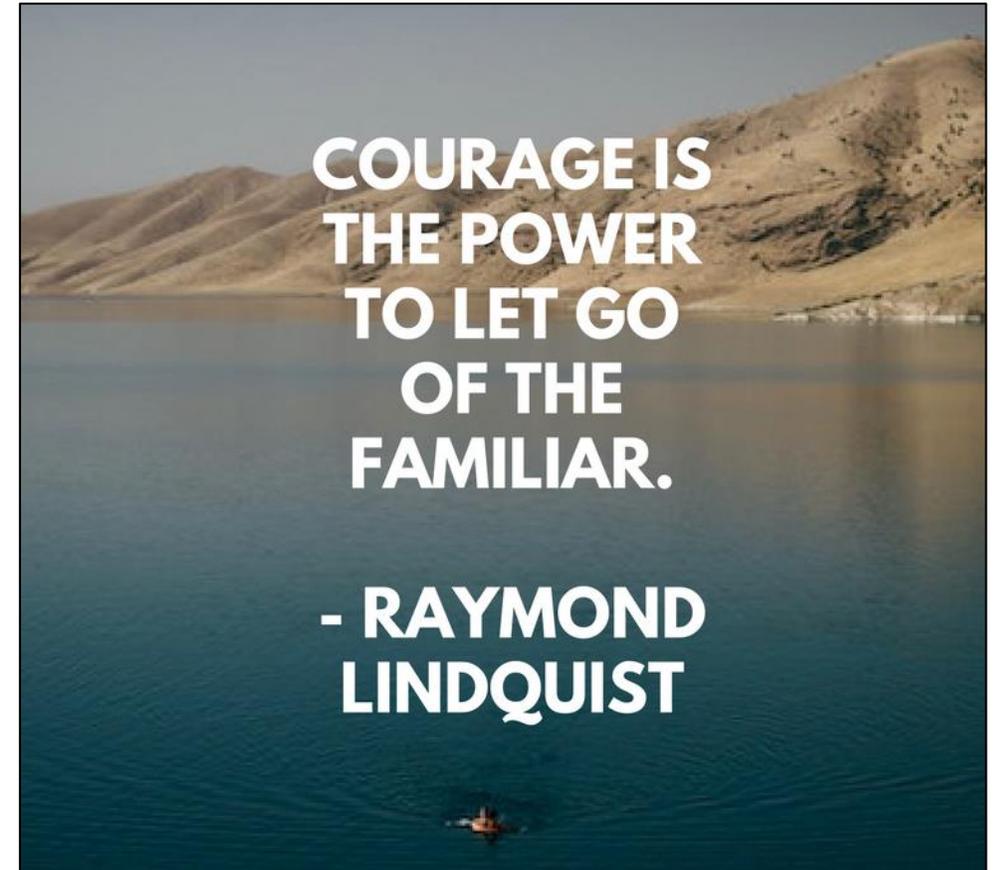
- Transition is a process, not a single event
- Know who's doing what during the transition process
  - Prescribing medications
  - Providing care for acute illnesses



***PRO TIP: Know which ED/hospital you will go to if your child needs emergency care during the transition period, especially when we're in the middle of a pandemic.***

# Lesson 8 – Don't forget that change is hard

- We are all naturally resistant to change
- Transition is a high stakes change for patients and their families
- The more we've navigated with our pediatric team, the harder it is to let them go



*A CHALLENGE FOR THE TRANSITION TEAM: How can we make adult healthcare less unfamiliar for families? What can we learn from families who have made the transition – the good, the bad, and the ugly?*