

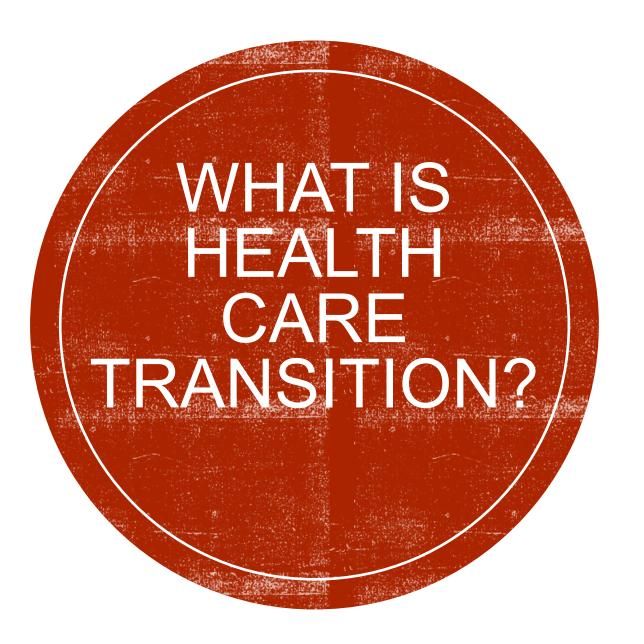
TRANSITION TO ADULT HEALTH CARE

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Kau'i Rezentes, Hilopa'a Family to Family, Mama of Ava



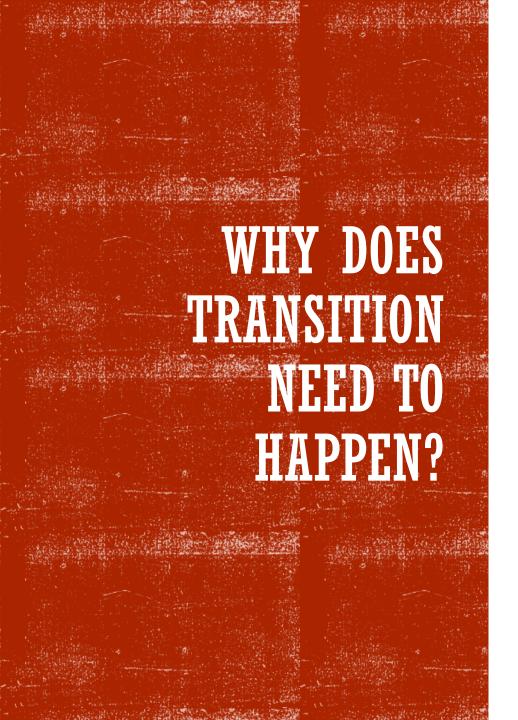
- Understand why transition is needed
- Obtain an overview of what the adult healthcare system looks like
- Start a simple timeline of key items that should be done
- Start thinking of a game plan...Envision the first visit with an adult provider



"Health care transition, or HCT, is the process of moving from a child/family-centered model of health care to an adult/patient-centered model of health care, with or without transferring to a new clinician. It involves planning, transfer, and integration into adult-centered health care."

"What is Health Care Transition?"

Got Transition, The National Alliance to Advance Adolescent
Health. www.gottransition.org/six-core-elements/.



- Once a child reaches age 18 (the age of majority) they are legally an adult, regardless of their capabilities
 - When applying for state/federal benefits, family income is no longer counted as the adult is considered a family of one
 - Legally, the individual will be looked upon to make their own life decisions
- As an adult, there are different medical issues that should be watched and screened for, in addition to any medical conditions that a person is born with

WHY IS THIS TRANSITION HARD?

ACTION

- Medical treatment for complex pediatric conditions dramatically improved lifespan for our keiki in the last few decades
- Society's views on disability have changed over the last few generations, going from institutionalizing individuals to encouraging community engagement and participation
- The prevalence of autism has dramatically increased in the last few decades

REACTION

 Adult medical providers may be unfamiliar with certain pediatric conditions and their treatments

 Adult medical providers may not be used to interacting with individuals with childhood disabilities and their families





3 AREAS OF CHANGE

INSURANCE

MEDICAL PROVIDERS

SYSTEM





Private Insurance

- Hawaii PrePaid
 Healthcare Law Employers are
 required to offer
 heath insurance to
 employees working
 at least ½ time
- Affordable Care
 Act- children can
 stay on parents
 insurance until 26
 years of age,
 regardless of
 employment/school
 status

State/Federal Insurance

- Children
 Quest/Medicaid
 coverage until 19th
 birthday, then need
 to apply for adult
 Quest/Medicaid
- Once individual reaches 18 years of age, income criteria is based on the individual's income alone, not family (this is also true for SSI)
- As of January 2023 adult Quest/Medicaid covers preventative dental



- Physicians-Some pediatricians and pediatric specialists see patients until age 18, some until 21
- Kapiolani Women and Children's Medical Center will not typically see males or females past the age of 21 or so.
- Shriner's Hospital see patients until 21 for the most part....please check if they have recommendations for wheelchair, ortho prosthetics follow up

PEDIATRICS ADULTS CARDIOLOGY

- Hypoplastic Left Heart Syndrome
- Tetralogy of Fallot
- Dextrocardia
- Double inlet L ventricle

- Coronary Artery Disease
- Heart Attacks
- Atrial fibrillation
- Congestive Heart Failure



SYSTEMS

Pediatrics

- Family Centered
- Longer length of appt
- Primary Care/Specialty Care affiliations
- Central pediatric center

Adult

- Patient Centered
- Shorter length of appt
- Primary care/Specialty Care affiliations possibly more distant
- Multiple adult hospitals



BARRIERS TO TRANSITION ADULT SIDE PEDIATRIC SIDE

- Lack of training in childhood onset conditions
- Doctor shortage
- Lack of insurance payment models for the level of care needed
- Lack of support staff and care coordination services
- Fragmentation of the adult health care system, poor integration with mental health and social services

- Communication gaps between Pediatric and Adult care
- Difficulty of pediatric provider to "let go"
- Lack of preparation for transition on both Pediatric and Adult side





- Preparing the future health workforce through education and training
 - Require medical students (MD, PA, NP) a minimum exposure to complex patients with childhood conditions
 - Establish fellowships focusing on YAMC
- Providing additional supports for the current primary care workforce
 - Create Regional Centers of Excellence for YAMC care to facilitate sharing of knowledge between pediatric and adult PCPs and specialist
- Supportive payment policy
 - Increase payment rates for PCP, add codes for complex YAMC care
 - Establish payment for care coordination
- Research on key needs and issues impacting on care of YAMC
- Coalition building for implementation and sustainability







Providers

- PCP, Specialists
- Adequate home nursing
- Specialty medicine provision

SSA/Medicaid

• Maintaining income eligibility



- Financial
 - ABLE accounts
 - Special Needs Trust
- Legal
 - Guardianship
 - Power of Attorney
 - Surrogate Decision Making-Health

Declaration of Authority to Act as Surrogate For a Patient*

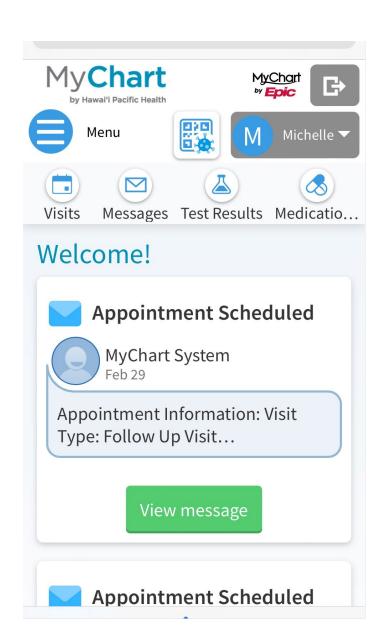
I,	, under penalty of false swearing,
(Name of Surrogate)	
provide the following statement of facts and circumstant	nces establishing my authority to act as
surrogate for	
(Name of Patient)	
who has been determined by the primary physician to lack capacity to make healthcare decisions	
and no agent or guardian has been appointed or the agen	nt or guardian is not reasonably available.
(MARK APPICABLE BOX)	
A. Patient-Designated Surrogate	
I have been provided information that the above nat	med patient personally informed the
supervising health care provider that I have been designated by the patient to make health-care	
decisions for the patient. This information was provided to me by the following means:	
decisions for the patient. This information was provided to me by the following means.	
(e.g., orally by (name of supervising health-care providerprimary physician/designee, health care provider or designee); by letter dated (copy attached); as recorded in patient's health-care record, etc.)	
OR	
B. Appointed ("Non-Designated") Surrogate	
I have been selected by consensus of interested persons of the above named patient to act	
as the patient's surrogate	1
1. I am an interested person based on my relationship to the patient as:	
(Mark or Circle One)	r uni punini uni
Spouse (not legally separated or estranged)	Reciprocal Beneficiary
Adult Child	Parent
Adult Sibling	Adult Grandchild
	
Other Adult who has exhibited special care and concern for the patient and who is familiar with the patient's wishes.	
for the patient and who is familiar with the patient's wishes.	

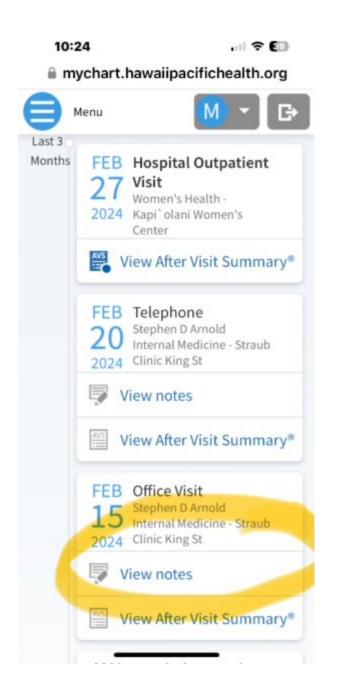


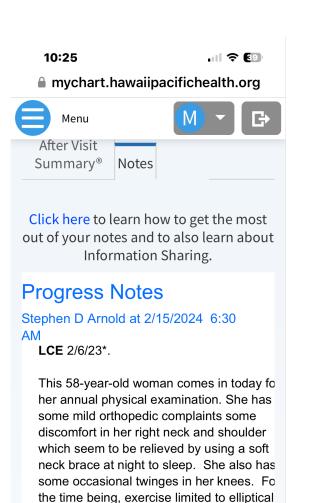
- Be Patient
- Ask around
- Complete legal paperwork
 - Legal guardianship- most restrictive
 Surrogate Decision Making for health care
 Power of Attorney (requires capacity)
- Schedule a well visit (annual physical, etc)...do not wait until an illness for the 1st visit
- Be prepared Have a list of questions or concerns that you want addressed
- Hospital systems
- Transition letter from your current PCP/specialist



- One of the largest EMRs in the United States
- Allows individuals to view entire MD note from 2021 (not just the after visit summary)
- Most recent test results as well as previous results can be viewed, this also includes MRIs, CT scans and X rays
- Parents/caregivers can request Proxy access to manage family's healthcare
- If seeing a health care provider who does not have Epic, can utilize Share Everywhere that allows a one time access to your My Chart to anyone with internet access. That individual would also be able to chart a note







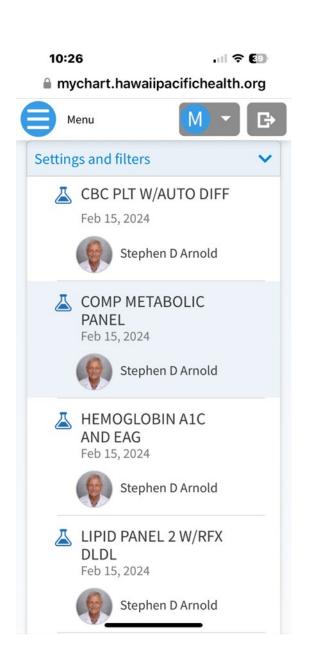
and to outrigger paddling. She was

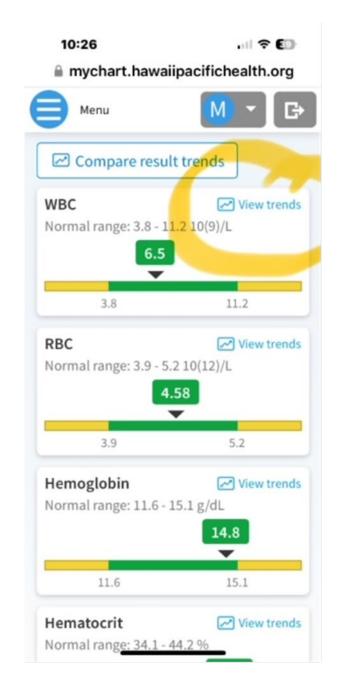
(which will end October 2024) with opportunity to do a lumpectomy at any

diagnosed with DCIS upper outer quadran left breast in May 2019 (E+//P+) -- she optobe in a trial of Tamoxifen daily for 5 year

time. She is followed by Dr. Jamie Fukui ar Dr. Laura Peterson. She opted not to do

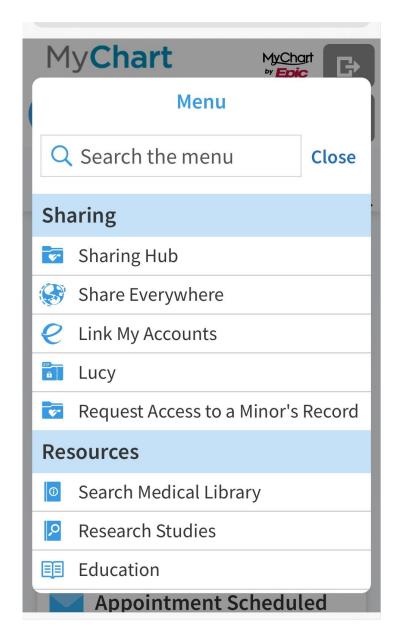


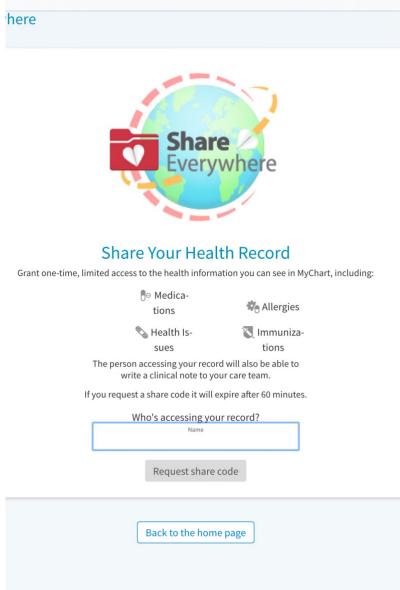


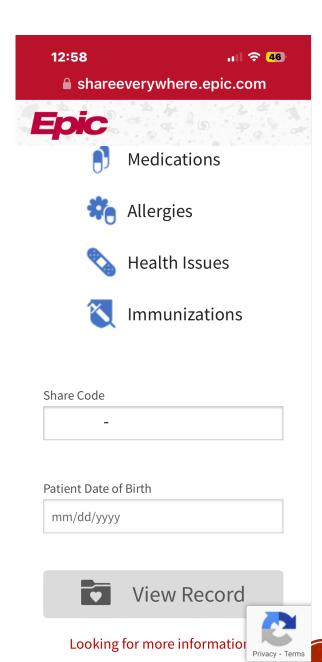










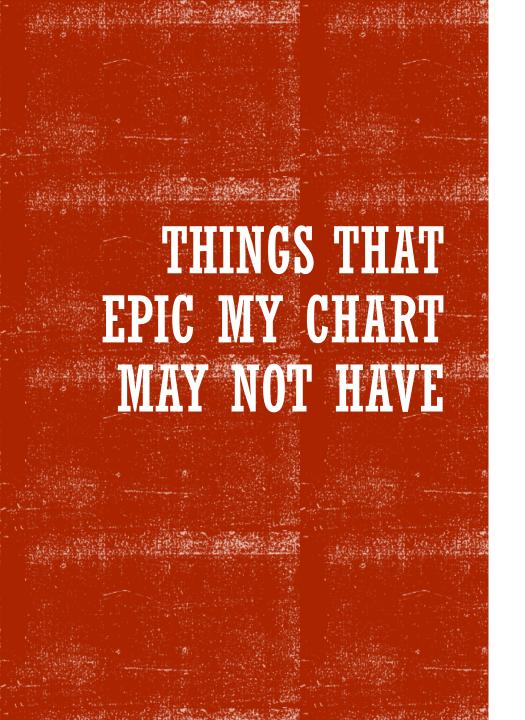




HAWAII HOSPITALS USING EPIC MY CHART

- HPH- Kapiolani, Straub Medical Center,
 Pali Momi Hospital, Wilcox Hospital
- Queen's Health System- Queen's Medical Center, Queen's West, (Wahiawa?)
- Hawaii Kaiser Permanente
- North Hawaii Medical Center
- Kona Community Hospital





- Information on equipment and/or medical supplies (i.e. Medline, Pharmacare, Optioncare, Apria)
- Hospitalizations
- Assessments/information from the DOE system (including reports is individual was accessing services provided by CAMHD via DOE)
- Nursing information if nursing provided by Medicaid/DDD
- Shriners Hospital Hawaii does not use Epic

THINGS TO KEEP IN MIND

In Hawaii, minors have the right to see mental health and fertility professionals without parents consent at age 14, so parents access to information gets limited in their minor child's My Chart. Please discuss with your primary care provider prior to 14 birthday, or if you experience lock out. PCP needs to fill out a Diminished Capacity form for parents to maintain full access

At age 18, parents completely lose proxy access....but your 18 year old can log on and give you proxy access via the Share Hub....or please bring up with your PCP to ensure your continued access. At this point, you may have to show legal paperwork



RESOURCES

- Got Transition: https://www.gottransition.org/
- Footsteps to Transition: https://footstepstotransition.weebly.com/
 - Turning 18, Health and Money: <u>Surrogate Decision Maker</u> (healthcare)
 Uniform Healthcare Decision
- Hilopa`a: Hawaii's family to family resource: https://www.hilopaa.org/
- Free template One Page Profiles: https://oregonisp.org/lppa/
- SPIN conference: https://spinconference.org/
 - Archived workshops 2016 Scott Suzuki, Esq: "Rights of Passage" (Guardianship and Alternatives)





QUESTIONS?

