

12 Steps to Help Your Child Transition

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Disclosures



Step 1: Start Early

- Start early: 12–14 years
- Transition refers to a shift in the responsibility of health care management from the family to the patient.
- Transfer is typically considered an event, whereas transition is conceptualized as a process.



Step 2: Educate Yourself and Your Child

Understanding Your Heart:

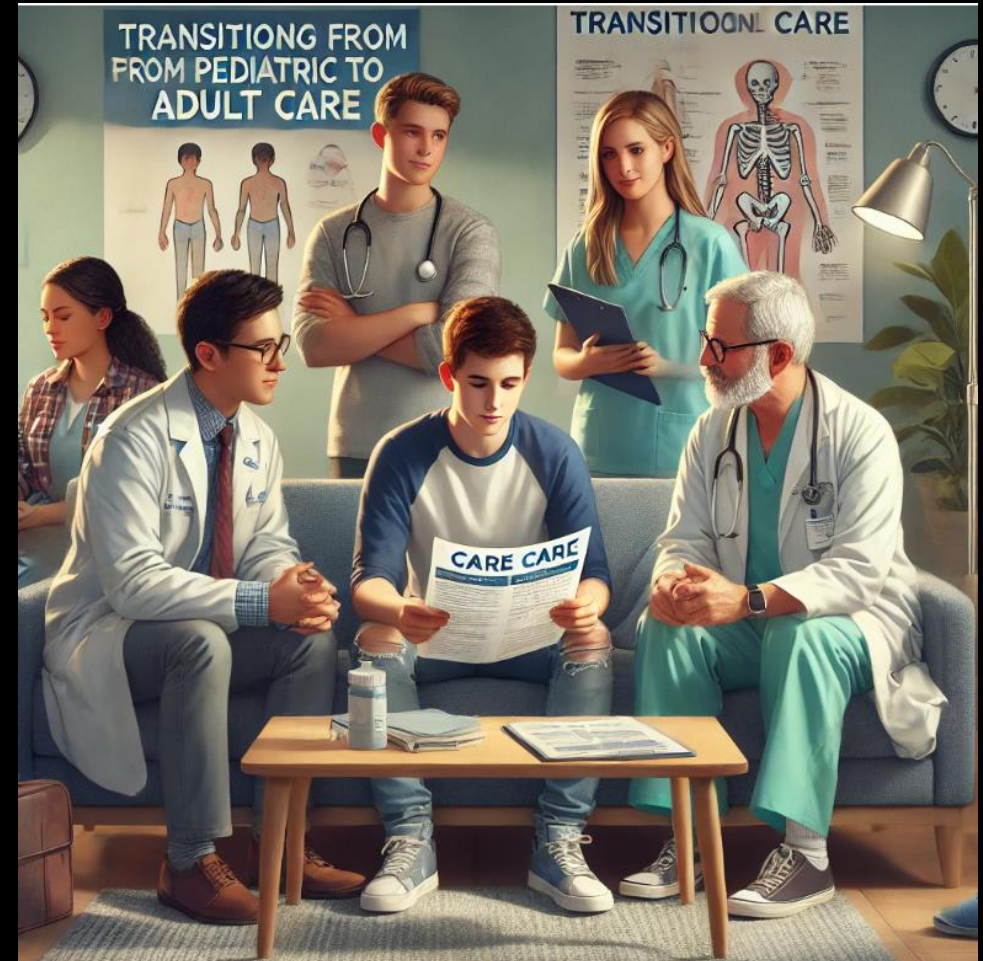
- **Learn About Your Condition:** Describe your medical condition

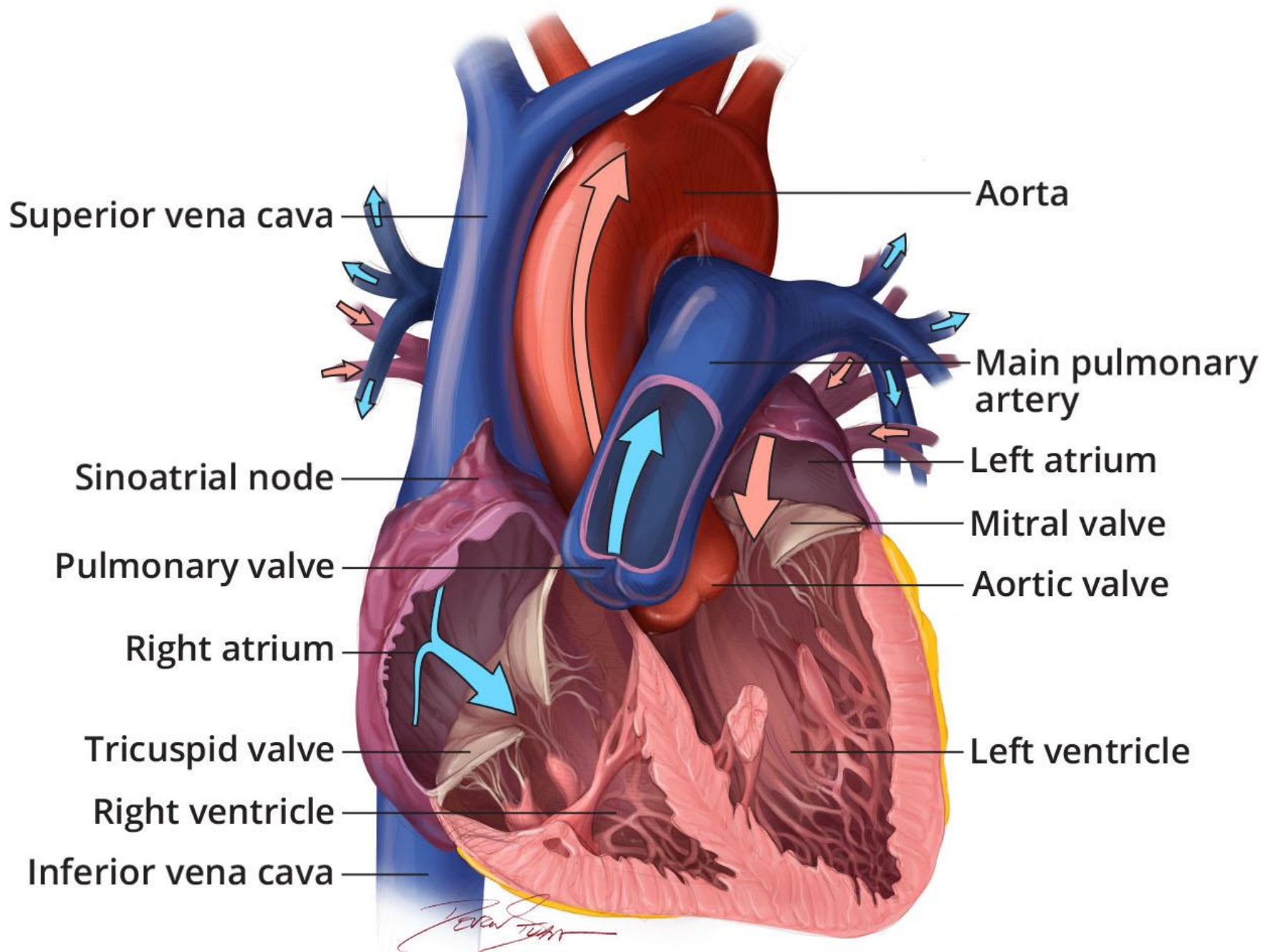
For Parents:

- **Discuss the Condition:** Explain in a way your child can understand.

Common Questions:

- **How Does My Heart Work?** Learn about your heart and how it's different..





Medical Passport

- Your Heart Condition: Learn about your specific condition, past surgeries, and future expectations (medical passport)
- Emergency Plan: typical oxygen saturation, ECG images
- Studies: last echo report and recent labs
- Dental care
- Activity restrictions

Personal Health Passport

A publication of the

**Adult
Congenital
Heart** 
Association

Sponsored by the



American College of Cardiology Foundation

Step 3: Involve Your Child in Health Decisions

- **Get Involved:** Ask questions about your health during doctor visits.
- **Schedule Appointments:** Start booking your own doctor visits and keep track of them
- **Support with Space:** Let your teen take charge but be there when needed.



Step 4: Build Resilience

- Teach problem-solving and coping strategies.
- Encourage healthy communication and self-advocacy.
- Celebrate milestones, even small ones, to boost confidence.



“Can something that has been broken, be put back together in a way that makes it more beautiful than ever before?”





Kintsugi

- The Japanese artists gather up these ceramic pieces and they put it back together. And so when the piece is put back together, it has these lines of gold that show exactly where the cracks are, but they're beautiful. I mean, these ceramics are astoundingly beautiful.



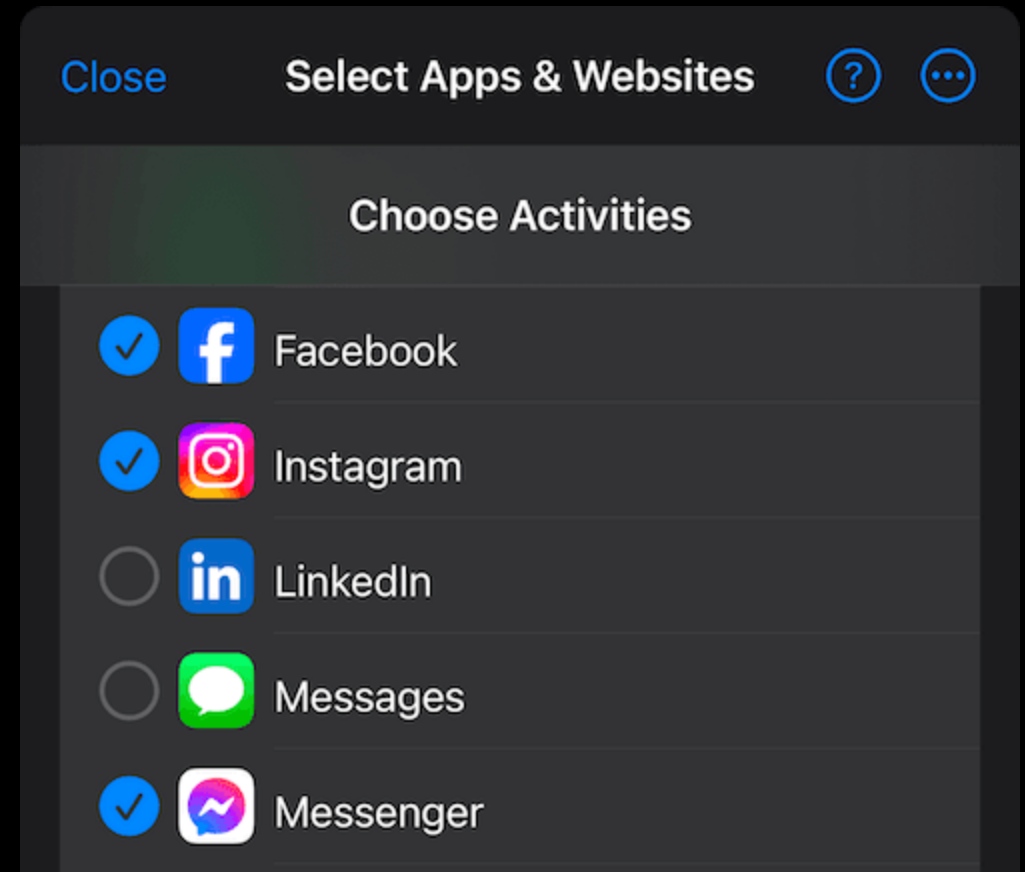
Step 5: Foster Independence

- Encourage your child to manage daily tasks (e.g., packing their medications, managing schoolwork).
- Create a balance between guidance and autonomy.
- Tools: chore charts, age-appropriate planners.



Step 6: Promote Healthy Habits

- Discuss the importance of nutrition, exercise, and sleep.
- Build routines that support physical and mental health.
- Tools: apps to track activity, family meals, and positive reinforcement.



EXERCISE

- **Keep Going:** Don't give up!
- **Small Wins Matter:** Set small goals, like walking a mile—every win counts.
- **Talk to Your Team:** Stay connected with your care team—they're here to help.
- **Check Your Progress:** Use tests to see how your heart is getting stronger.
- **Stick With It:** Keep at it—every bit of effort adds up!



Step 7: Address Spiritual, Emotional and Social Needs

- Acknowledge the emotional challenges of growing up with CHD.
- Connect them with peers who share similar experiences (support groups, camps).
- Encourage open communication about feeling



Camp del Corazon: free summer camp

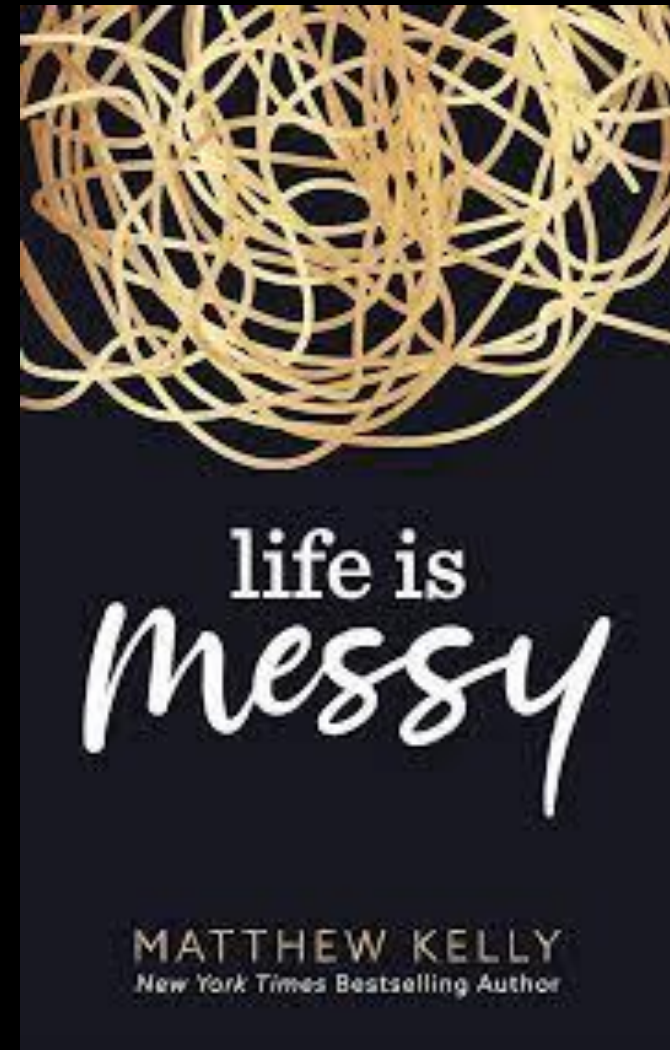


Mental health support



“The greatest threat to your happiness and wholeness is your unrecognized spiritual needs.”

- “That’s thirteen words that took me a lifetime to formulate. It’s an idea that I have known, forgotten, and remembered again too many times to count.
- I mean it with all sincerity, that if you sat with that single sentence for thirty minutes every day for a year, pondering, reflecting, wondering, meditating upon what it means to you, it would be time well spent.”



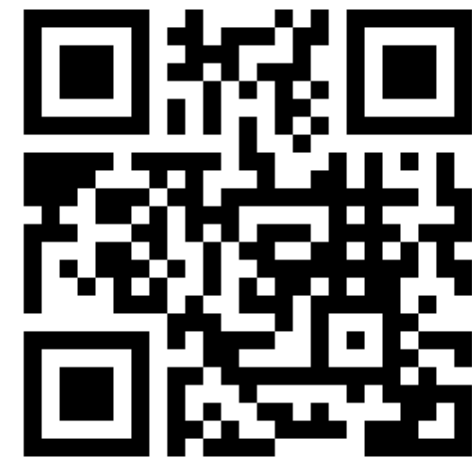
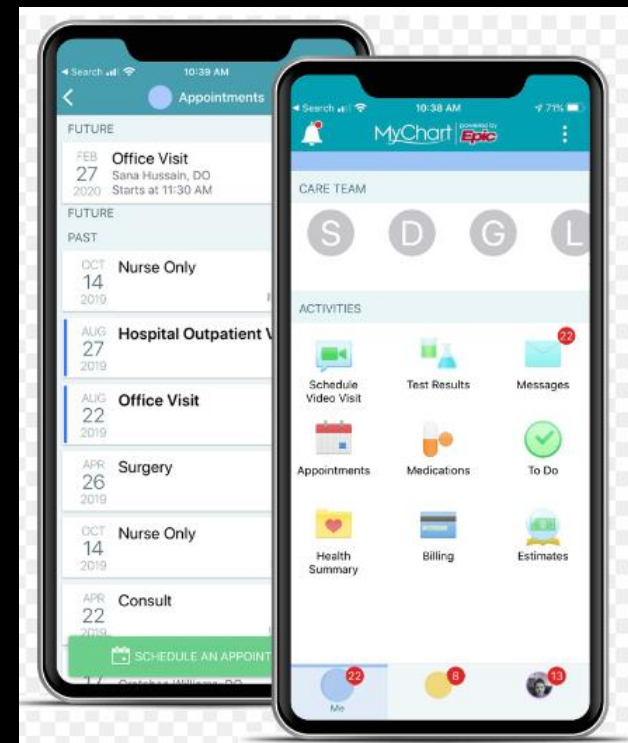
Step 8: Focus on Education and School Resources

- Collaborate with teachers and school staff.
- Use individualized education plans (IEPs) or 504 plans if necessary.
- Ensure accommodations are in place for health needs (e.g., extra time for assignments, frequent breaks).



Step 9: Use Technology

- Teach your child how to use MyChart or similar tools to track their health.
- Encourage them to schedule appointments or refill prescriptions online.
- Tools: Health tracking apps, digital calendars.



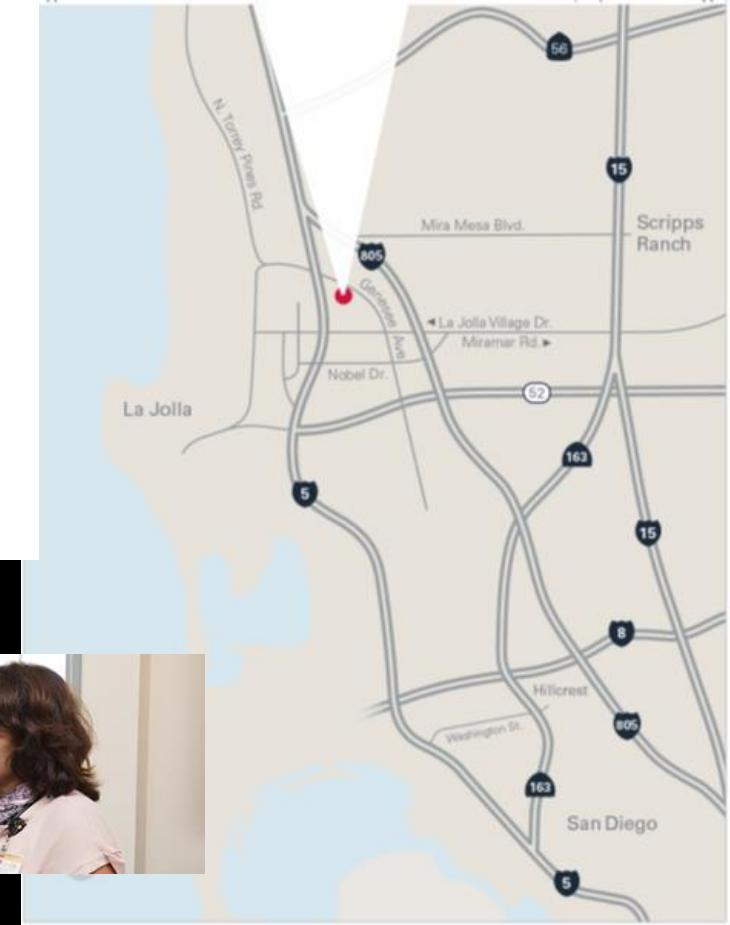
Step 10: Prepare for Adult Healthcare

- Discuss the eventual transition from pediatric to adult care.
- Teach them how to communicate with healthcare providers effectively.
- Introduce the adult cardiology team early, if possible.



The adult congenital heart disease program at UC San Diego Health

- New and Existing Patients
 - 858-246-3271
- Referring Physicians
 - 858-246-5700
- Sulpizio Cardiovascular Center
- 9434 Medical Center Drive
- La Jolla CA, 92037 858-657-8530



Key Essentials for Health Maintenance



- Health Insurance: Provides access to essential healthcare services, medications, and emergency care.
- Primary care adult provider: Addresses adult-specific health needs.
- Dentist: Prevents dental issues from escalating into severe health problems.



Step 11: Encourage Lifelong Learning

- Discuss the importance of understanding their condition as it evolves.
- Encourage them to ask questions, stay informed, and take ownership of their care.
- Tools: educational resources, webinars, or conferences.

ACHA Wellness
Wednesdays



Fontan Outcomes Network: resources for patients and families



High School Career Exploration Resources



- School-Based Career Resources: counselor
- Online Career Exploration Tools: My Next Move,
- Career Assessments & Personality Tests
- Work & Volunteering Opportunities
- College & Post-High School Planning: Trade schools, community colleges, apprenticeships
- Next Steps: Meet with a counselor, take assessments, explore careers!



College Resources for Students

- 📌 Register with the Disability Services Office (DSO)
- 📌 Provide Medical Documentation (Letter from Cardiologist)
- 📌 Request Accommodations



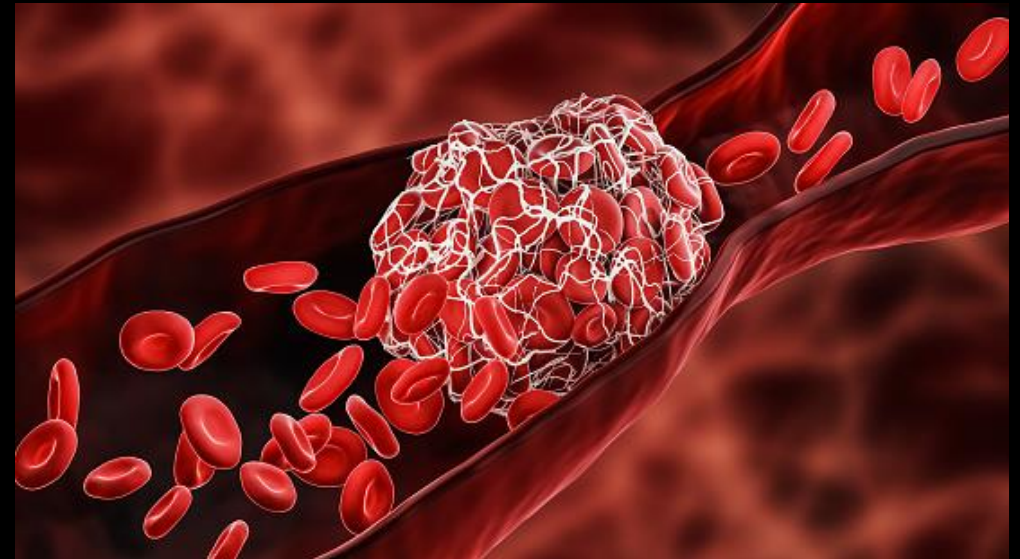
What are some common tests?

- An ECG (electrocardiogram)
- 24-hour Holter monitor
- An echo (transthoracic echocardiogram)
- Exercise stress test
- Labs



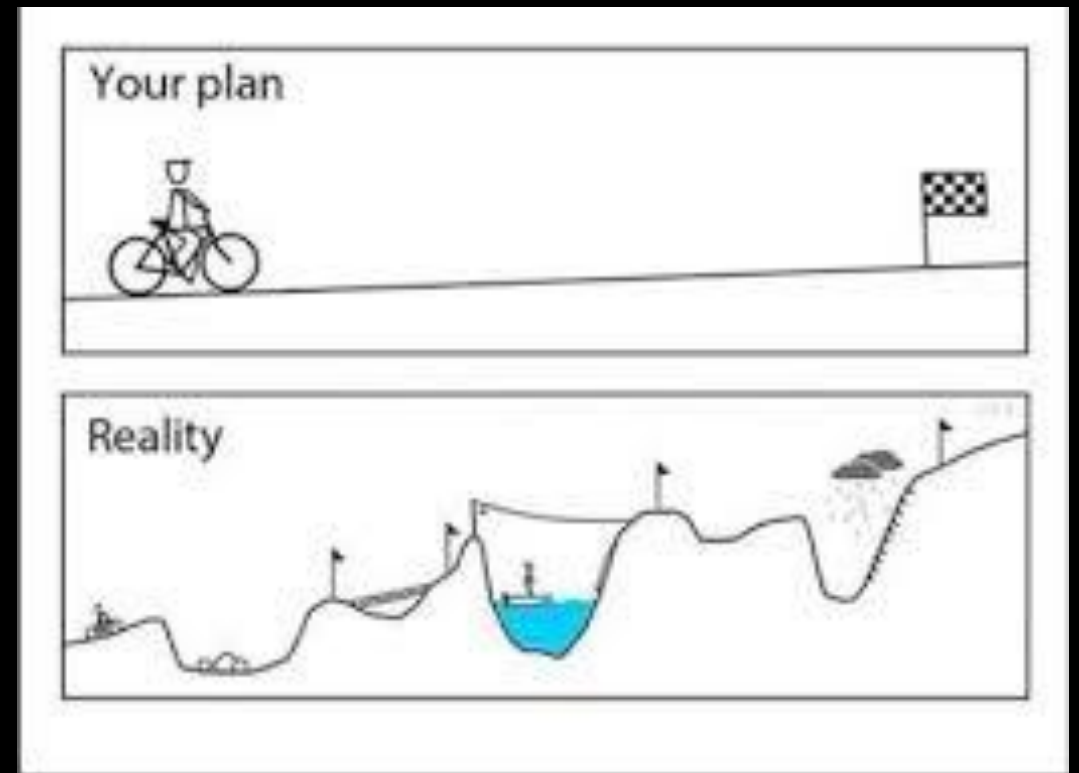
What are some of the more common medications?

- Aspirin
- Coumadin
- Enalapril, Lisinopril.
- Lasix, aldactazide
- Tadalafil, sildenafil
- Nadolol, sotalol



Step 12: Celebrate Growth

- Recognize and celebrate your child's achievements throughout the journey.
- Acknowledge the effort both you and your child have put into transitioning.
- Reassure them that it's okay to seek help when needed.



Volunteer, Driver's License, and Work

- Volunteering: Enhances leadership and teamwork skills.
- Driver's License: Promotes independence and responsibility.
- Work Experience: Provides financial literacy and budgeting skills.



You've Got This!

- You're Not Alone
- Take It One Step at a Time
- Empower Yourself
- Your Future is Full of Possibilities:
- Hope and Resilience: Each challenge makes you stronger.
- Look Forward with Confidence: The future is bright—anything is possible with support.



Transitional Program at RCHSD

- Transitional clinic at RCHSD
- Clinic dedicated for transitional needs only
 - Tele-med visit is an option
 - Recommended visits
 - [12-14 years old](#)
 - [15-17 years old](#)
 - [>18 years old](#)
- Rady Children's Hospital-San Diego Rose Pavilion,
1st Floor South 3020 Children's Way San Diego,
CA 92120
- [Phone: 858-966-5855](tel:858-966-5855) [Fax: 858-966-7903](tel:858-966-7903)



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