

Fontan ACTION Plan *for Patients*

Tips for Good Health and Recognizing Symptoms

The road to the Fontan was long! Now that you're here, it is important to 1.) keep your body and mind healthy AND 2.) to know if you are having symptoms that could mean that the Fontan isn't working as well as it should. This is a guide to help you do both.



You're doing great if:

- You don't have any major symptoms
- You're keeping up with your cardiologist appointments
- You're staying active, eating healthy, and feeling okay emotionally



Check out MyACTIONEducation.org to learn about heart failure, medicines, and therapies.



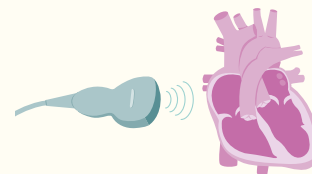
If you have any of the following symptoms or test results, check in with your cardiologist to talk about whether you might need to see a heart failure specialist.

Symptoms:

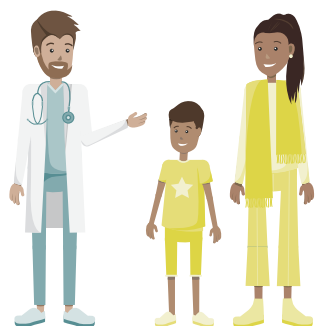
- More tired than usual or not able to walk far or exercise anymore
- Getting out of breath easily or having trouble keeping up with your friends
- Swelling in the belly or legs, or around the eyes
- Skin looks more blue or your oxygen saturation is lower
- Coughing up blood or thick rubbery mucous (called casts)

Test Results Showing:

- Heart isn't squeezing well (moderate or more dysfunction of the ventricle)
- Leaky heart valves (moderate or more leaking of the valves)
- Liver or kidney function is not normal (creatinine >2 times normal and/or a GFR <90)
- Your heart pressures are high on catheter tests (Fontan Pressure >15, Cardiac Index <2.5, EDP >12)
- You've been in the hospital for too much fluid (and needed medicine through an IV), rhythm issues, or tummy swelling



NOTE: The next page has a list of recommended testing by age.



What is a Heart Failure Specialist and why see one?

A heart failure specialist is a heart doctor who helps people when their hearts aren't working as well as they should. This could be a weak heart or a heart with leaky valves.

You might only see this doctor one time, just to get their opinion. Or they may become part of your care team if your heart needs more help. This might mean special treatments like strong medicines, a heart pump, or even a heart transplant.

Your regular cardiologist and the heart failure specialist work together to take care of you.

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What tests do you need? And how often?

These are tests recommended based on expert consensus, however specific tests and frequency of tests can vary based on individual needs. Ask your cardiologist if you have any questions about any of these tests

Test or Visit	Children (<12 years)	Adolescent (12–17 years)	Adults (>18 years)
Cardiologist Visit (in-person)	At least once per year		
Electrocardiogram (ECG) (heart rhythm test)	At least once per year		
Echocardiogram (Echo) (heart ultrasound)	At least once per year		
Heart Rhythm Monitor	Every 2–3 years	Every 1–2 years	
Exercise Test (6 minute walk test OR exercise stress test)	Every 2–3 years	Every 1–2 years	
Cardiac Magnetic Resonance Imaging (MRI)	Every 3–5 years	Every 2–3 years	
Cardiac Catheterization	Only if needed	Every 10 years	
Blood Tests (Labs)*	Every 3 years	Every 1–3 years	Every 1–2 years
Abdominal Ultrasound (U/S) +/- Elastography	Every 3 years	Every 1–3 years	Every 1–2 years
Liver Ultrasound	Every 3 years	Every 1–3 years	Every 1–2 years
Liver Magnetic Resonance Imaging (MRI)	Not needed unless there are nodules on the liver ultrasound		Every 2 years
Neurodevelopment Check	Once before starting grade school	At the start of middle school or high school	Once IF never done as a child
Mental Health Screening	At least once per year		

* Labs = Blood and urine tests to check how your liver, kidneys and body are doing.