



Transitioning to Adult Care: A Toolkit for Teen Cardiomyopathy Patients

As a teenager getting ready for adulthood, you can start to take control of your health and learn how to manage your cardiomyopathy. As you approach 18, you will need to start transitioning your care from a pediatric cardiologist to an adult cardiologist. The resources in this toolkit are to guide you so that the transition goes smoothly.

The forms included in the toolkit are designed to help you decide when you are ready to be your own health spokesperson. It covers preparing for a doctor's appointment, talking with medical professionals about your condition, and keeping track of your medical information. It is a good idea to fill out the forms, save them on your computer and/or a flash drive and bring a copy with you to your medical appointments. It is a good idea to review the forms every 3-4 months to see if any information needs to be updated.

- Health readiness assessment
- Medical health summary
- Transition plan

Important Transition Points

When you're transitioning from child to adult heart care, it's important to keep these important points in mind:

- Continue to educate yourself about your type of cardiomyopathy and the need for specialized care throughout adulthood.
- Speak to your new cardiologist about your condition, concerns and symptoms.
- Take medication as directed.
- Address new lifestyle considerations: exercise, physical restrictions, contraceptives.
- Obtain insurance coverage (health and life insurance, know what your plan covers).
- Review other adult health problems and their relation to, or impact on, cardiomyopathy.
- Consider logistics of receiving care: transportation to appointments, financial considerations, finding a new adult cardiologist if relocating.

Transitioning means taking responsibility for your healthcare. Remember that treatment and management of cardiomyopathy is an ongoing process and the transition to adult care marks the beginning of

a new chapter of taking care of yourself and your health. Also remember that while you are assuming more responsibility for your health, there are many people in your life who are able to help and support you. Reach out to your support system if you need help with the transition. It is an adjustment, but with good planning, tools, resources and support, you will be successful in taking control of your health care.

Transition Resources

There are medical apps available that can be especially helpful during your transition to care, and throughout adulthood.

- **My Chart:** gives patients access to lab results, appointment information, current medications, immunization history and more.
play.google.com/store/apps/details?id=epic.mychart.android&hl=en
- **My Medications:** patients can store, carry and share their critical medical information (medications, emergency contacts).
ama-assn.org/ama/pub/about-ama/apps/my-medications.page
- **MedCoach Medication Reminder:** helps patients remember to take their medications at the right time each day.
itunes.apple.com/us/app/medcoach-medication-reminder/id443065594
- **Med Helper:** keeps track of prescriptions, reminds patients when medications need to be taken, notifies patients when doctors appointments are scheduled and provides alerts when medications are running low.
play.google.com/store/apps/details?id=com.earthflare.android.medhelper.lite

CCF Resources and Member Registration

CCF's website provides detailed information about cardiomyopathy under *About the Disease* and *Living with PCM* sections and offers a wide range of patient support services and resources under the *Family Resource* section. If you have not done so already, we encourage you to register as an individual member of CCF before you transition to adult care so that you can remain connected to CCF. As a registered CCF member you will receive important updates on services, programs, research and developments in cardiomyopathy, and upcoming CCF events. Registration is free and can be completed online at childrenscardiomyopathy.org.

Sources:

This toolkit was developed using resources from the New England Consortium Transition Toolkit and Nationwide Children's Hospital: Adolescent & Adult Congenital Heart Disease Transition Program.

DISCLAIMER: This fact sheet is meant to provide general information and is not intended to be complete or replace the advice given by a medical professional. Cardiomyopathy is a highly variable disease. The information provided here should not be used for diagnosing or treating cardiomyopathy.

Health Readiness Assessment

Take this simple test to determine if you are can handle your own healthcare as an independent adult.

1.	I know my height, weight, birth date, and social security number	Yes	No
2.	I know the name of my condition	Yes	No
3.	I know my genotype or genetic status	Yes	No
4.	I can tell you about my condition and explain my health care needs	Yes	No
5.	I know what kind of medical insurance I have	Yes	No
6.	I know where to find my medical records	Yes	No
7.	I know who to ask about getting my own health insurance	Yes	No
8.	I know the basic treatment for my condition	Yes	No
9.	I know what my diet should include and not include	Yes	No
10.	I know how to prepare my own food	Yes	No
11.	I know how to shop for my own food	Yes	No
12.	I know the names of my supplements and medicines	Yes	No
13.	I know how to order my medications or get my prescriptions filled	Yes	No
14.	I know the symptoms and medical problems related to my condition	Yes	No
15.	I visit my cardiomyopathy specialist regularly	Yes	No
16.	I have discussed issues about sex with my doctor	Yes	No
17.	I know how to get birth control and how to stay protected against sexually transmitted diseases (STDs)	Yes	No
18.	I have discussed the use of tobacco, alcohol and drugs with my doctor	Yes	No
19.	I know how to schedule a doctor's appointment	Yes	No
20.	I keep a schedule of medical appointments on my calendar	Yes	No
21.	I can get myself to medical appointments (or can arrange transportation myself)	Yes	No
22.	I know who to call in case of an emergency	Yes	No
23.	I prepare questions for my health care provider before appointments	Yes	No
24.	I have a support network for my condition	Yes	No

Number of times you checked **YES**: _____

17 to 24 statements – great work! You are already taking full responsibility for your health care. The following transition documents will help you become a stronger health advocate.

8 to 16 statements – you are on the right path! You are actively taking on many important responsibilities in your health care. The following transition documents will help you answer YES to more of these questions.

0 to 7 statements – let's get started! Transitioning health care to adult providers and becoming a better health advocate for yourself takes time and planning. Now is a perfect time to start! Pick a few of the previous responsibilities from the list and spend the next month doing them. The transition documents will make this much easier.

Retake this assessment every month until you have answered all of the tasks with a YES!

Adapted from the New England Consortium of Metabolic Programs

Medical Health Summary

Date Updated: _____

Last Name		First Name	
Birthdate	Gender	Weight	Height
Address			
City		State	Zip Code

Insurance Name _____

Insurance ID & Group # _____

Insurance Address & Phone Number _____

Type of Cardiomyopathy _____ Date of Diagnosis _____

Medications/Supplements and Dosages _____

Allergies to Food, Drugs and Other Substances _____

Emergency Contact Name & Relationship _____ Phone Number _____

Pharmacy Name _____ Phone Number _____

Immunizations	Immunization Date
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Other medical information:

Transition Plan for: _____

Primary Care Physician _____ Phone Number _____

Email _____

Pediatrician _____ Phone Number _____

Email _____

Cardiomyopathy Specialist _____ Phone Number _____

Email _____

Other Health Care Provider _____ Phone Number _____

Email _____

Emergency Contact Name & Relationship _____ Phone Number _____

Medical Background

Treatment Status: _____

Current Mediations/Treatments: _____

Allergies/Adverse Reactions: _____

Past Medical Concerns or Hospitalizations: _____

Living Situation/Employment: _____

Mental Health Status/Cognitive Status: _____

Other Health Risks: _____

To enhance collaboration, each party shall handle the following responsibilities:

Cardiologist will:

- Obtain necessary labs/tests and communicate results to the patient.
- Prescribe cardiomyopathy-related medications/supplements.
- Advise on a cardiac emergency protocol.

Patient will:

- Remember to take medications.
- Order and pick up medications/supplements.
- Adhere to medical appointments.
- Communicate updates on cardiac condition to primary care physician.
- Speak to cardiologist about any cardiac medical concerns.

Primary Care Physician will:

- Monitor patient's general health.
- Update cardiomyopathy specialist with important patient information.
- Contact cardiomyopathy specialist with medical concerns.