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.*

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>I know my height, weight, birth date, and social security number</td>
<td>Yes</td>
</tr>
<tr>
<td>2.</td>
<td>I know the name of my condition</td>
<td>Yes</td>
</tr>
<tr>
<td>3.</td>
<td>I know my genotype or genetic status</td>
<td>Yes</td>
</tr>
<tr>
<td>4.</td>
<td>I can tell you about my condition and explain my health care needs</td>
<td>Yes</td>
</tr>
<tr>
<td>5.</td>
<td>I know what kind of medical insurance I have</td>
<td>Yes</td>
</tr>
<tr>
<td>6.</td>
<td>I know where to find my medical records</td>
<td>Yes</td>
</tr>
<tr>
<td>7.</td>
<td>I know who to ask about getting my own health insurance</td>
<td>Yes</td>
</tr>
<tr>
<td>8.</td>
<td>I know the basic treatment for my condition</td>
<td>Yes</td>
</tr>
<tr>
<td>9.</td>
<td>I know what my diet should include and not include</td>
<td>Yes</td>
</tr>
<tr>
<td>10.</td>
<td>I know how to prepare my own food</td>
<td>Yes</td>
</tr>
<tr>
<td>11.</td>
<td>I know how to shop for my own food</td>
<td>Yes</td>
</tr>
<tr>
<td>12.</td>
<td>I know the names of my supplements and medicines</td>
<td>Yes</td>
</tr>
<tr>
<td>13.</td>
<td>I know how to order my medications or get my prescriptions filled</td>
<td>Yes</td>
</tr>
<tr>
<td>14.</td>
<td>I know the symptoms and medical problems related to my condition</td>
<td>Yes</td>
</tr>
<tr>
<td>15.</td>
<td>I visit my cardiomyopathy specialist regularly</td>
<td>Yes</td>
</tr>
<tr>
<td>16.</td>
<td>I have discussed issues about sex with my doctor</td>
<td>Yes</td>
</tr>
<tr>
<td>17.</td>
<td>I know how to get birth control and how to stay protected against sexually transmitted diseases (STDs)</td>
<td>Yes</td>
</tr>
<tr>
<td>18.</td>
<td>I have discussed the use of tobacco, alcohol and drugs with my doctor</td>
<td>Yes</td>
</tr>
<tr>
<td>19.</td>
<td>I know how to schedule a doctor's appointment</td>
<td>Yes</td>
</tr>
<tr>
<td>20.</td>
<td>I keep a schedule of medical appointments on my calendar</td>
<td>Yes</td>
</tr>
<tr>
<td>21.</td>
<td>I can get myself to medical appointments (or can arrange transportation myself)</td>
<td>Yes</td>
</tr>
<tr>
<td>22.</td>
<td>I know who to call in case of an emergency</td>
<td>Yes</td>
</tr>
<tr>
<td>23.</td>
<td>I prepare questions for my health care provider before appointments</td>
<td>Yes</td>
</tr>
<tr>
<td>24.</td>
<td>I have a support network for my condition</td>
<td>Yes</td>
</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Last Name</th>
<th>First Name</th>
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<th>Birthday</th>
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Address

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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:

Adapted from the New England Consortium of Metabolic Programs
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.

Adapted from the New England Consortium of Metabolic Programs