

# I Have What?

The following was provided by someone who has been living with ECD for a while. He thought it might be helpful to new patients if there was something to give newly diagnosed patients so they might know how to begin taking care of themselves. He believes attitude has been important in his management of the disease, and has found that other patients he talks with feel similar. He is hoping the following information will help patients and caregivers, as everyone is searching for information.

1. Attitude is Everything
  - a. Keep a positive attitude
  - b. Keep moving
  - c. Live life as normally as possible
  
2. Medical stuff
  - a. Let someone advocate for you
  - b. Keep copies of your medical records
  - c. Communication is key
    - i. Have your doctors communicate with each other
    - ii. Let you doctor know help is a phone call or e-mail away - the ECD Global Alliance can provide contact information for medical researchers who are studying ECD
  
3. You are what you eat
  - a. Eat a healthy well balanced diet.
  - b. Understand the diet that best suits your particular health needs.
  - c. Do I need supplements?
    - i. Know your body's chemistry
    - ii. Speak with your doctor, let her know what you are taking, follow their recommendations.
    - iii. Talk to others in the community to know what to look for.
  
4. Use it or lose it.
  - a. Exercise, however you can
  - b. Investigate Physical therapy options, or individualized program for your needs.
  - c. Don't shy away from things that are difficult, unless dangerous
  
5. Get involved
  - a. Stand up for yourself
  - b. We're all in this together

For more information, contact the ECD Global Alliance, [support@erdheim-chester.org](mailto:support@erdheim-chester.org).