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Samuel F. Sears, Lawrence Woodrow, Katherine Cutitta, Jessica Ford, Julie B. Shea and John Cahill

*Circulation*. 2013;127:e525-e528

doi: 10.1161/CIRCULATIONAHA.112.000734

*Circulation* is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231

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Print ISSN: 0009-7322. Online ISSN: 1524-4539

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## A Patient's Guide to Living Confidently With Chronic Heart Failure

Samuel F. Sears, PhD; Lawrence Woodrow, MA; Katherine Cutitta, MA; Jessica Ford, MA;  
Julie B. Shea, MS, RNCS; John Cahill, MD

**C**hronic heart failure (CHF) refers to the ongoing condition of your heart's inability to pump sufficient blood to meet your body's demands. The name of any medical condition that includes the word failure can be intimidating, particularly when it concerns your heart. After all, failure implies there is no hope, right? Wrong! The medical term "failure" can be demoralizing, but patients can identify ways to increase the chances of living longer and living well with CHF. To live successfully with CHF, it is important to develop confidence. For heart patients, confidence can refer to self-assurance, positive and healthy actions, and expectations that desirable health outcomes can be achieved. CHF is challenging because it requires patients and families to understand and monitor CHF symptoms, manage distress, accept the value of the implantable cardioverter-defibrillator (ICD), and pursue quality of life (QoL). For CHF patients, these ambitious goals involve developing confidence in each aspect of the treatment plan, spanning disease confidence, device confidence, and QoL confidence.

### Disease Confidence

Disease confidence is a way of thinking and feeling about your disease that results in a greater sense of personal security and empowerment. Disease confidence can be developed by taking appropriate self-care in managing your CHF. Self-care involves a level of understanding about your medical condition, as well as making informed decisions about your care to minimize symptoms and/or to respond effectively to symptoms that may occur.<sup>1</sup>

### Understanding CHF

CHF is a complicated disease state that is unique for each individual. For example, some patients will experience frequent bouts of excessive fluid retention, whereas others will note mild shortness of breath with exertion. The first and most important step in becoming disease confident is being knowledgeable about CHF and how it affects you. Similar to mastering subjects in school, a patient with heart failure can and should learn the ways in which the disease is affecting his or her body. The more you know about CHF, the more confident you will feel about monitoring

symptoms, adhering to treatment, and managing psychological distress.

### Symptom Monitoring

CHF is a disease that may result in shortness of breath, excessive fluid and weight gain, and poor exercise tolerance. Table 1 displays common symptoms that you may experience with CHF. Sudden weight gain (3 pounds in 24 hours) may indicate that you are building up or retaining extra fluid. This symptom may be a sign of your heart's trouble in circulating blood adequately. Weighing yourself daily provides information to prevent CHF through early intervention with medications such as diuretics (water or fluid pills). Elevated blood pressure and heart rate can also signal a change in your heart's function and prompt a medication adjustment. Checking your daily blood pressure and heart rate enables you to monitor for significant changes that should be reported promptly to your healthcare providers. Some patients with CHF like to create charts to report daily weights and blood pressure to share with their medical team. Figure 1 shows an example chart.

From the Departments of Psychology (S.F.S., L.W., K.C., J.F.) and Cardiovascular Sciences (S.F.S., J.C.), East Carolina University, Greenville, NC; and Brigham and Women's Hospital (J.B.S.), Boston, MA.

Correspondence to Samuel F. Sears, PhD, East Carolina University Department of Psychology, 215 Rawl Hall, Greenville, NC 27858. E-mail searss@ecu.edu

(*Circulation*. 2013;127:e525-e528.)

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*Circulation* is available at <http://circ.ahajournals.org>

DOI: 10.1161/CIRCULATIONAHA.112.000734

**Table 1. Common Symptoms of Chronic Heart Failure**

Shortness of breath
Swelling in hands and feet (abdomen)
Lack of energy for activity
Productive cough
Increased urination (decreased)
Mental confusion or concentration difficulties
Difficulty sleeping because of breathing problems

**Treatment Adherence**

Treatment adherence refers to such things as taking your prescribed medications, maintaining a low-salt diet, limiting alcohol use, staying active, stopping smoking, and monitoring symptoms (eg, weight gain). The degree to which you adhere to your treatment plan is an important factor for determining your future well-being. Your healthcare team may assume that you are following your treatment plan perfectly. Clear and honest communication about the typical challenges or barriers to following doctor’s orders helps your healthcare team work with you toward improved follow-through.

Many CHF patients find it challenging to monitor and change so many daily behaviors and activities. The challenges involve both physical limitations and mental reactions. Both depression and anxiety are highly

linked to difficulty adhering to treatment plans and result in decreased QoL.<sup>2</sup> It is understandable that body changes and problematic symptoms could increase your worries and possibly lead to feeling discouraged. The healthcare team understands these typical emotional reactions and can help you manage these concerns.

**Managing Psychosocial Distress**

Depression is common and can occur in ≈50% of patients with CHF.<sup>3</sup> However, patients with CHF often increase their medical adherence once their depression is treated.<sup>4</sup> Depressive symptoms can look very similar to some heart failure symptoms, which include fatigue, trouble sleeping, loss of interest in activities, inability to concentrate, feelings of hopelessness, and change in appetite. Anxiety is also common in heart failure patients, which includes such symptoms as excessive worry, fear, dread, muscle tension, sweating, heart palpitations, shortness of breath, and fatigue.

Depression and anxiety can be controlled with medications, as well as psychotherapy (or counseling) techniques, such as cognitive behavioral therapy. This therapy incorporates education, processing and reorganizing thoughts to create a healthier outlook on the disease state, and a behavioral

component that involves resuming previously enjoyed activities. If you think that you may be experiencing unhealthy levels of depression or anxiety, let your healthcare provider know immediately. Your physician will be able to prescribe helpful medication or refer you to a mental health provider as needed.

**Device Confidence**

Some people with heart failure may experience abnormal heart beats that may result in sudden cardiac arrest. The ICD is a surgically implanted medical device that monitors and delivers a shock to restart the heart if it goes into a dangerous rhythm. Your doctor will advise you if your condition would be better managed with the help of an ICD. This small device has been proven to save lives<sup>5</sup> and can be viewed as an insurance policy against sudden cardiac arrest.

Below are some strategies for successfully coping with the challenges of living with an ICD. Table 2 lists topics and Web addresses of other *Circulation* Patient Pages that explain in greater detail the points made below.

**Understanding the ICD**

As an ICD patient, you are asked to rely on technology for protection. You must recognize that it may take some time

Below please complete your daily action passport to do your part in managing your health.

Date	Check Weight	Take Meds	Exercise / Daily Activity	Check Blood Pressure	Meet Sodium Goal	Enjoyable Activity
05/13/11 *Example*	Weight Unchanged	Took all meds on time	30 minutes of activity	120 / 80 Or less	No food more than 20% daily value Sodium	Walked with my grandson today
	1-2 pound gain		Less than 30 minutes of activity	120 – 139/ 80 - 89	1 – 2 foods greater than 20% daily value sodium	
	3 – 5 pound gain	Missed dose	No activity	140 or higher / 90 or higher	3 or more foods greater than 20% daily value sodium	
—/—/—	Weight Unchanged	Took all meds on time	30 minutes of activity	120 / 80 Or less	No food more than 20% daily value Sodium	
	1-2 pound gain		Less than 30 minutes	120 – 139/ 80 - 89	1 – 2 foods greater than 20% daily value sodium	
	3 – 5 pound gain	Missed dose	No activity	140 or higher / 90 or higher	3 or more foods greater than 20% daily value sodium	

Figure 1. Sample activity checklist table.

**Table 2. Patient Pages for People Living With ICDs, Including the Author, Topic, Article Title, and Address**

Author	Topic	Title	Web Address
Reiffel and Dizon	ICD education and quality of life question and answer	The implantable cardioverter defibrillator: patient perspective <sup>9</sup>	<a href="http://circ.ahajournals.org/content/105/9/1022.full.pdf">http://circ.ahajournals.org/content/105/9/1022.full.pdf</a>
Sears, Shea, and Conti	Coping with shock	How to respond to an implantable cardioverter-defibrillator shock <sup>7</sup>	<a href="http://circ.ahajournals.org/content/111/23/e380.full">http://circ.ahajournals.org/content/111/23/e380.full</a>
Hazelton, Sears, Kirian, Matchett, and Shea	Information for spouses	Coping with my partner's ICD and cardiac disease <sup>10</sup>	<a href="http://circ.ahajournals.org/content/120/10/e73.full">http://circ.ahajournals.org/content/120/10/e73.full</a>
Vazquez, Shea, Sears, and Vazquez	Sexual health	Sexual health for patients with an implantable cardioverter defibrillator <sup>11</sup>	<a href="http://circ.ahajournals.org/content/122/13/e465.full">http://circ.ahajournals.org/content/122/13/e465.full</a>
Kirian, Sears, and Shea	Device recall	How to respond to an implantable cardioverter defibrillator recall <sup>12</sup>	<a href="http://circ.ahajournals.org/content/119/5/e189.full">http://circ.ahajournals.org/content/119/5/e189.full</a>
Flavell and Stevenson	Diagnosis and treatment information	Taking heart with heart failure <sup>13</sup>	<a href="http://circ.ahajournals.org/content/104/18/e89.full">http://circ.ahajournals.org/content/104/18/e89.full</a>
Alpert	Diet and nutritional suggestions	Nutritional advice for the patient with heart disease <sup>14</sup>	<a href="http://circ.ahajournals.org/content/124/10/e258.full">http://circ.ahajournals.org/content/124/10/e258.full</a>
Myers	Physical activity	Exercise and cardiovascular health <sup>15</sup>	<a href="http://circ.ahajournals.org/content/107/1/e2.full">http://circ.ahajournals.org/content/107/1/e2.full</a>

ICD indicates implantable cardioverter-defibrillator.

to regain your sense of security regarding your medical condition. Learning about the purpose and function of your ICD will help you feel more comfortable with your device.

### ICD Shock

Defibrillating shocks can be disruptive, discomforting, and painful. In fact, most patients rate them about a 6 out of 10 on a pain scale.<sup>6</sup> It is important to have a shock plan (see Table 3) so that you do not spend time worrying about what to do if your ICD fires. If you experience 1 shock and feel fine afterward, contact your healthcare provider as soon as possible. If you are shocked more than once or do not feel well after a shock, call 911 immediately. After a shock, try to maintain a survivorship mentality by reminding yourself that the ICD is there to protect you and that it worked exactly as it should.

### Family

Coping with heart failure and living with an ICD can also be distressing for spouses and other family members. It is common for spouses and caregivers to have even more anxiety and depression than patients.<sup>8</sup> Help empower your family by educating them about your ICD and cardiac condition.

### QoL Confidence

Developing disease and device confidence helps lead to an improved QoL. Other important aspects of QoL confidence include re-engaging in activities and activating emotional and practical help and support.

### Re-engage in Activities

Achieving desirable QoL involves getting back to doing as many of the same enjoyable activities as possible that you engaged in before CHF. This may also be an important opportunity to begin

new activities that will help you regain good QoL. Walking, bicycling, social events with friends, joining a support group for CHF or ICD patients, and hobbies are all examples of activities that may help you regain life satisfaction. Our actions have a tremendous effect on our sense of well-being. Make sure that you talk with your healthcare provider to get specific guidelines on activities that are safe and then make a point of doing them.

### Activating Support

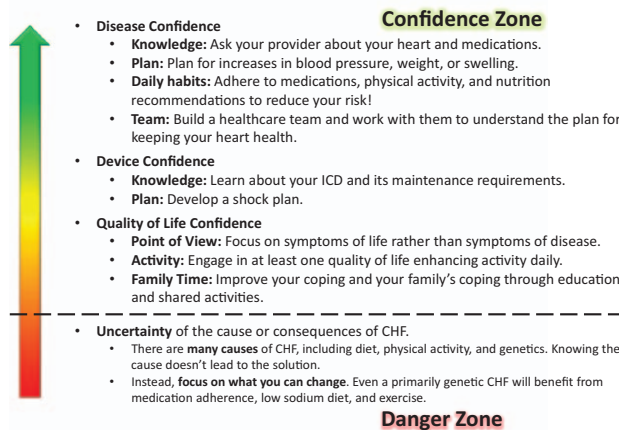
Engage your family, friends, and healthcare providers in helping you to live successfully with CHF. Be willing to talk with them about your needs, concerns, and fears. The challenges of living with CHF may be greatly reduced by taking advantage of a strong social support network. Get involved in fun and enjoyable activities together. Also, take care of yourself and encourage

**Table 3. Shock Plan Table<sup>7</sup>**

Event	Symptoms	Action
Received ICD shock	Feel fine immediately	Call heart doctor to discuss the event and arrange appropriate follow-up
Received ICD shock	Experiencing chest pain/pressure, shortness of breath, rapid heart action; feel dizzy, confused, or not well	Seek medical attention immediately
Received $\geq 2$ ICD shocks within 24 h	Feel fine or ill	Seek medical attention immediately

ICD indicates implantable cardioverter-defibrillator.

## Living Confidently with Chronic Heart Failure



**Figure 2.** Living confidently with chronic heart failure.

your spouse or partner to take time to relax and take care of himself or herself as well. It is also important to regain emotional and sexual intimacy with your spouse or partner, particularly if CHF has disrupted these important aspects of your relationship. If you did not spend much time activating support before CHF, then make this an opportunity to do so now.

### Conclusion

Figure 2 provides a summary of key points for successfully managing CHF. It is important to know and believe that you, along with your family, friends, and healthcare team, are equipped to handle this challenge. Make it a point to develop disease, device, and QoL confidence so that you can live confidently with CHF!

### Disclosures

Dr Sears serves as a consultant to Medtronic and has had research grants from Medtronic in the past 2 years. These funds are directed to East Carolina University. Dr Sears also has received speaker honoraria from Medtronic, Boston Scientific, St. Jude Medical, and Biotronik.

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