

WHAT PROBLEMS? There are consequences—other than the direct (or seemingly unrelated) physical ones—resulting from a sudden cardiac arrest (SCA) or from an impending or actual implantation of an ICD. An SCAA-sponsored study found that over a third of the SCA Survivors responding to a written survey indicated worse emotional status after an SCA than before. The study revealed that psychological issues included:

Anxiety · Fear of physical exertion · Not understanding the cardiac event · Depression · Family emotional reaction · Financial impact · Concerns about becoming a “burden”

COPING IS A CRITICAL ISSUE FOR SURVIVORS AND ICD IMPLANTEES

In addition to what the Study revealed, there are the myriad of questions of a large scope and variety asked by Survivors and ICD implantees and their families, even long after their cardiac events that SCAA and its members and followers have responded to. For example, SCAA has sponsored an online support group since 2007 called the Sudden Cardiac Arrest Association Support Community. <http://www.inspire.com/groups/sudden-cardiac-arrest-association/>. This robust support group, with over ten thousand responses, has generated interest in many of the psychological, physiological and other issues facing SCA survivors, Implantees and their families. The SCAA site has dealt with symptoms of visual vertigo, sensitivity to certain sounds, seemingly unrelated physical pain, PSVT, broken leads, spousal concerns, the desire to “take it (the ICD) out,” pocket infections, phantom shock, dreams and scores of other topics. Additionally, there are several closed support groups (limited to survivors and implantees) on FACEBOOK. One such ICD related site has over 1400 members and an estimated greater than twenty thousand postings. Because it is a closed site, many of the postings are more personal in nature. For instance, there are pictures of scars, and more delicate issues discussed such as lactation, issues concerning sexual relations, religious concerns and suicide. It is a fact that lives have been saved because of these sites, as members have been convinced not to terminate their lives.

In addition to the various online resources, members of SCAA chapters around the country have engaged in supporting members of their communities who have suffered an SCA or have been implanted, as well as members of the families of both groups. We are now taking this program national.

WHY THE COPE-LINE?—Simply stated, people enjoy talking with one another and often get more out of a conversation than reading information online. There is more of a chance of making an emotional connection when talking with someone than reading an on line response. That increases the chances of in-depth communication, satisfaction in getting answers, ability to clarify answers that are not quite there; and to obtain healing through human connection. Our initial COPE Aides are survivors and implantees with years of experience in talking with peers about issues common to our unique group. This peer to peer communication has proven very useful to family members as well as survivors and implantees and they are invited to use the COPE-LINE, as well.

WHAT’S COMING?—Soon we will be adding to our cadre of AIDEs, spouses of Survivors and Implantees, and those who have lost love ones to SCA.

WHAT DO I DO NEXT?—It is as simple as picking up your phone. Please hit the COPE tab on our website for full instructions on leaving a message on the COPE-LINE and for other helpful information on how the process works. You can also call the COPE-LINE and receive oral instructions on how to proceed.

IMPORTANT NOTICE—The information conveyed on the COPE-LINE is not intended to provide medical advice of any kind. And none of the remarks made by an Aide during a conversation should be construed as providing medical advice. Anyone feeling pain or having medical issues should not use the COPE-LINE to seek assistance. Seek medical care from a medical provider or call 911 immediately. The COPE-LINE does not provide real time response. We attempt to answer all calls within twenty four hours of receipt.