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# Addressing the Needs of Survivors and Loved Ones

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[SCA News](#) [1]



Kelly Sawyer, MD, Jennifer Chap,  
Susan Koeppen, Mary Newman

PITTSBURGH, PA--The Sudden Cardiac Arrest Foundation presented a well-attended session, “Addressing the Needs of Survivors and Loved Ones,” during the Emergency Cardiovascular Care Update earlier this month in Las Vegas. Speakers included Mary Newman, Foundation president, Susan Koeppen, a TV news anchor and survivor, Kelly Sawyer, MD, an emergency physician and survivor, and Jennifer Chap, a marketing professional who saved her husband’s life with CPR.

## **The SCA Survivor Network and Literature on SCA Survival**

Newman reported on the characteristics of members of the Foundation’s SCA Survivor Network, an online community for SCA survivors, noting that most members are white, male, and have implantable cardioverter defibrillators (ICDs). Nearly 40% of members were 40-years-old or less at the time of their event.

She also summarized themes from scientific literature on survivors, noting that many survivors experience the following: depression, anxiety, memory loss, easily triggered crying, fear of the ICD firing—or fear of not having an ICD, guilt, a heightened sense of smell, sleep disturbances, a perception of vulnerability, a sense of destiny, a sense of urgency, the ability to “size up” others more readily, greater love of family and friends and greater empathy toward others. She said the literature also suggests that family members of survivors suffer from fear, a sense of isolation, a lack of social support, psychosomatic problems, and need for support to prevent burnout.

Lessons from the limited, but growing body of literature about SCA survivors and families suggest:

- SCA is an individual *and* a family crisis
- Learning new knowledge is difficult at a time when stress is high and coping strategies are low
- Recovery is both physical and emotional.

The Foundation's SCA Survivor Network is designed to help address some of these concerns by providing a platform for survivors to share their experiences, find other survivors, and help one another in the healing process—and get involved in the cause by participating in research, media outreach, legislative advocacy, and speaking opportunities. The Foundation also provides an online community for family members of survivors and those who did not survive, plus others interested in the cause.

### **A Qualitative Survey on Survival After Cardiac Arrest**

Dr. Sawyer, from Beaumont Hospital in Royal Oak, Michigan shared her personal reflections as both a survivor and an emergency physician who has studied the use of mild therapeutic hypothermia for cardiac arrest survivors. She then presented the results of a qualitative survey recently conducted among members of the Foundation's SCA Survivor Network.

The most common self-identified challenges reported by survey respondents were anxiety, memory problems, re-establishing a routine, and depression. These were also identified as key issues by family members who completed the survey.

Unfortunately, most survivors reported they received very little information about what to expect after hospital discharge. When asked, "What information were you given regarding what to expect after discharge?," the most common answer was "Nothing."

"The hospital "lost me" and did not communicate to me or my husband," said one respondent. "I didn't realize the severity of my recovery," said another. "It was like it was so routine," said a third respondent. "They popped in the 'box,' gave me a temporary card, and sent me on my way. It all seemed so impersonal—but to me it was very personal."

Survivors also expressed frustration that the public does not understand the difference between sudden cardiac arrest and a heart attack, and fails to recognize that SCA is so common.

The implications of the survey are:

- Empowering survivors and family members through information about SCA can be an effective tool
- A post-SCA transitional protocol could enhance quality of life and reduce family conflict and stress during recovery.
- Educating the public on the difference between SCA and a heart attack could improve support for publicly available AEDs and community-wide CPR training.

### **Reflections of a Survivor**

The Foundation's National Spokesperson, Susan Koeppen, an anchor at KDKA TV in Pittsburgh, had previously presented an overview of her case as keynote speaker at the Emergency Cardiovascular Care Update. (See [Dip to Black](#) [2].) During this followup session, she shared her personal reflections about the emotional issues her family faced following her survival from cardiac arrest. She spoke of her children's fears about losing their mother, her husband's fears that she would not "be Susan" when she woke up from her medically induced coma, and her mother's propensity to check in regularly to make sure she is still okay. She shared that one recent evening when she was planting flowers at dusk, her young daughter watched from the window, then begged Susan to come in, since she was afraid to go to sleep without the

security of a goodnight kiss. Susan also shared her renewed appreciation for life and the joy of spending time with her family—and finally completing the Pittsburgh Marathon.

## Reflections of a Rescuer

Jennifer Chap, of Orlando, Florida, shared her personal reflections as a lay rescuer and wife. She recounted that it was the family cat, “Buddy,” who first alerted her that something was terribly wrong. Jen and her husband Rick work from home, and at Buddy’s urging, Jen left her office to find Rick unconscious in another room. She called 911 and started CPR. “It was surreal to have my husband lying lifeless on the floor and that Bee Gees song in my head,” she said.

They would later return to personally thank everyone involved in Rick’s survival, including the Orlando Fire Department 911 dispatcher and responders at Station 6, emergency department and ICU providers, the interventional cardiologist, the critical care hospitalist, and cardiac rehab unit providers at the Orlando Health Heart Institute.

ECCU 2012 represented a turning point for the Chaps in the healing process. Since then, their journey has been buoyed by a profound sense of gratitude. Each year, they celebrate Rick’s re-birthday, sharing memories that might not have been. And they are paying it forward by supporting local and national awareness and outreach initiatives.

These are Jen’s secrets for “pushing through”:

1. Giving herself permission to feel, knowing the event happened to both of them
2. Getting help to work through post traumatic stress disorder, recognizing that her memories (unlike Rick’s) are visceral
3. Living in gratitude for everyone who helped save Rick’s life
4. Daring to share to make a difference for others.

***To join the SCA Survivor Network, an online community for survivors, [click here](#).*** <sup>[3]</sup>

***To join the SCA Network, an online community for families and others affected by sudden cardiac arrest, [click here](#).*** <sup>[4]</sup>.

-Mary Newman



wkushubar wrote 4 min 58 sec ago

## Survey Result Synopsis

Spot on in results assessment. Physical causes of cardiac arrest are well-treated with some therapy to get you back to walking, talking, writing, etc.

Mental well-being not addressed at all. To me, that was and is the challenging byproduct of my cardiac

arrest. Especially memory loss and changes in self-perception and social awareness,

Bill Kushubar

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