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Coping With My Partner's ICD and Cardiac Disease

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The Implantable Cardioverter Defibrillator (ICD) is an implantable biomedical device that monitors and treats abnormal heartbeats when they occur. The device is attached to the heart with 1 to 3 leads that carry information from the heart to the ICD, allowing it to record heart function, selectively provide pacing if the heart beats too fast or too slowly, and/or administer high-energy shocks if more serious heart rhythms are detected. The primary purpose of the ICD is to prevent premature sudden cardiac death. However, the device can also provide a sense of security, which allows resumption of normal life activities.

Current research has suggested that psychological distress can occur in ICD patients and their partners. Anxiety may be more prevalent in ICD partners than in ICD patients.¹ ICD partners are particularly worried about ICD shocks, even more so than the patients themselves.² This Patient Page describes common challenges associated with the psychological adjustment of ICD partners and offers possible strategies to consider in managing these difficulties. A summary is provided in the Table.

Adjusting to the ICD

Once the ICD has been implanted, lifestyle adjustments can be made that promote health and well-being. However, such adjustments may take time and a bit of work; most people take about 3 months to adjust to such major life changes. A patient's adjustment often mirrors the partner's adjustment, so effective coping can improve both of your lives.

Patient Acceptance

Patient acceptance refers to how well an individual adapts to the ICD and accepts its pros and cons. Patients and partners may differ on how well they accept the device. The hope for ICD patients is that they reengage with the confidence of having "an emergency room in the chest"; yet some patients experience difficulty and avoid activities they previously enjoyed, such as going places or interacting with other people. In fact, both ICD recipients and partners may experience distress caused by fear of shock, body image concerns, or fear that the device will malfunction or be recalled. Learning about cardiac disease and ICDs often can improve confidence.

Suggested Strategy 1: Learn as Much as Possible About the ICD

Misunderstandings about the ICD's purpose and function are very common. Do not let a lack of knowledge stand in the way of accepting the value of the ICD. Some patients and their partners report that they did not know the device would save the patient's life, much less that it would do so by administering a shock to the heart! Many resources are available, including talking with your healthcare providers and researching information on the internet.

Suggested Strategy 2: Acknowledge the Benefits of the ICD

The purpose of the ICD is to reduce the risk of dying suddenly from a dangerous heart rhythm abnormality. Allow your thoughts to influence your partner's for the better.

Returning to Life

Some partners may find it difficult to get back into the rhythm of life after the device is implanted. Partners may experience increased demands, such as attending doctor's visits, learning about heart disease and treatments, and having concerns about the loved one's health, capabilities, and future.

The information contained in this *Circulation* Cardiology Patient Page is not a substitute for medical advice, and the American Heart Association recommends consultation with your doctor or healthcare professional.

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Table. Summary of Suggested Strategies for the Partners of Patients With ICDs

Goals	Common Difficulties	Suggested Strategies
Adjusting to the ICD	Patient acceptance	1. Learn as much as possible about the ICD. 2. Acknowledge the benefits of the ICD.
	Returning to life	3. Use the expert support of providers. 4. Assist your loved one in performing daily and ICD-related tasks.
	Role changes	5. Discuss each other's roles in caring for ICD-related matters. 6. Focus on the positive aspects of caregiving. 7. Be assertive in expressing your struggles.
Managing psychological distress	General anxiety	8. Learn and implement relaxation techniques.
	Shock anxiety	9. Learn how to respond to ICD shock.
	Depression	10. Seek support. 11. Know when to seek professional help.
Maintaining relationships	Behavioral avoidance	12. Participate in physical and social activities.
	Discord	13. Listen and be patient.
	Sexual intimacy	14. Seek subtle ways to become more intimate.
	Overprotection	15. Encourage the patient to live life fully.
	Effect on children	16. Inform children about shock and how the ICD works.

Suggested Strategy 3: Use the Expert Support of Healthcare Providers

Request educational materials from your providers. Do not hesitate to ask questions about the ICD and medications. Knowledge will lead to a feeling of greater confidence in your ability to act as a caregiver.

Suggested Strategy 4: Assist Your Loved One in Performing Daily and ICD-Related Tasks

Emotional support and lending a helping hand can have remarkable effects on the physical health and quality of life of both the patient and the partner. Imagine that you are both on the same team with the shared goal of living well.

Role Changes

A sense of equality may no longer be present when one member of a couple becomes the caregiver. Partners may feel the weight of assuming more responsibilities in the relationship. Partners may find that less attention is paid to them by other family or friends because of the increased attention given to the ICD patient. With the focus of concern on the patient and the

patient's medical condition, some partners may find it difficult to discuss their own concerns and may feel that their own worries pale in comparison to those of their partner. While the patient does have a serious medical condition, the concerns of the partner remain important.

Suggested Strategy 5: Discuss Each Other's Roles in Caring for ICD-Related Matters

Your beliefs about caregiving responsibilities may be different from the patient's beliefs. It is important to understand each other's expectations to avoid misunderstandings. Occasionally, limits may need to be set to avoid overprotectiveness.

Suggested Strategy 6: Focus on the Positive Aspects of Caregiving

Optimism improves mental and physical health in both the caregiver and the patient.³ Although being a caregiver can at times be overwhelming, providing love, support, and compassion for the loved one can be honorable and rewarding, and it can bring you closer together.

Suggested Strategy 7: Be Assertive in Expressing Your Struggles

Clear communication can help couples cope positively with life after an ICD and the role changes that may follow. Communicating concerns can enhance the couple's bond by allowing for reassurance, understanding, and support.

Managing Psychological Distress

Psychological distress, including anxiety and depression, is common for both patients and partners. Although the distress is not easy, there are several ways to manage such negative feelings.

General Anxiety

Anxiety refers to how partners worry about the ICD patient, the strain of caregiving, and the stress of everyday life. When either member of a couple withdraws because of anxiety, the other will tend to withdraw as well.

Suggested Strategy 8: Learn and Implement Relaxation Techniques

Anxiety is often triggered by negative thinking about potential problems. Relaxation techniques can help manage anxiety by focusing attention on a sense of calm while helping the person gain control over internal physiological events. Diaphragmatic breathing, progressive muscle relaxation, and imagery are a few techniques that work quite well. See "How to Respond to an Implantable Cardioverter-Defibrillator Shock" for a guide to the diaphragmatic breathing relaxation exercise.³

Shock Anxiety

A partner may experience fear or anxiety as the loved one faces potential shock or other medical complications. This is quite understandable, because watching a loved one receive a powerful and potentially painful shock can be an unpleasant experience.

Suggested Strategy 9: Learn How to Respond to ICD Shock

Approximately one third of patients who receive an ICD may experience a shock during the first year.⁴ With this in mind, having a plan and knowing

the best way to respond to shock will likely reduce anxiety. Part of proper planning is educating yourself on why shocks occur and understanding the various ways the device treats abnormal heart rhythms. In general, if 1 shock occurs, the patient's provider should be called and made aware of the event. If 2 or more shocks occur, you should call the patient's provider and get the patient to the emergency room for further evaluation. If the patient ever loses consciousness, or has repetitive shocks, call 9-1-1 or the emergency number in your area.

Depression

Emotional lows can be common during times of increased stress and responsibility. Partners may feel that some of their former freedoms are diminished because of their increased caregiver responsibilities. Furthermore, some partners may feel helpless as they anticipate their loved one receiving an ICD shock.

Suggested Strategy 10: Seek Support

Partners and patients can help each other by providing emotional support. This can be accomplished when they allow each other to voice concerns, fears, frustrations, or feelings of sadness. ICD support groups may be available locally or online.

Suggested Strategy 11: Know When to Seek Professional Help

It is important to distinguish clinical depression from normal mood fluctuations due to situational changes. Depression is often associated with changes in sleeping and eating, low mood, and/or a lack of pleasure. If either the patient or the partner experiences suicidal ideation or intention, seek professional help.

Behavioral Avoidance

Many partners and patients withdraw from social or physical activities, often under the misconception that they are helping to prevent or reduce the chance of shock. Some partners fear shock in public, and the fear can lead to the couple's avoiding social situations. However, research indicates that

shocks cannot be induced by participating in most activities, nor can they be avoided by ceasing normal activities of daily living, such as exercising and visiting with friends. If patient and partner withdraw from family outings, social gatherings, or physical activities, the health and quality of life of both individuals are negatively affected.

Suggested Strategy 11: Participate in Physical and Social Activities

Positive experiences lead to greater comfort when engaging in activities. By providing support, the partner can help the patient live with confidence. Examples include going for a walk, going out to dinner with friends, or attending an ICD support group meeting. Remember, for the majority of ICD patients, physical activity does not lead to shock. Talk to your health-care providers about what activities are safe.

Maintaining Relationships

The added stress of cardiac disease can lead to partners feeling disconnected from the patient or others in their life.

Discord

Discord in relationships may develop as the stress of medical difficulties comes between loved ones. As a partner you may disagree with the patient on a variety of topics, including the decision to get the ICD, the amount of activity after surgery, eating habits, level of dependence/independence, and many other issues. These disagreements may cause tension among couples, but they are typical of the ongoing process of adjustment.

Suggested Strategy 12: Listen and Be Patient

Providing undivided attention and listening to our loved ones without immediately judging or voicing our disagreement can often improve outcomes. Reflect on the patient's own words about the effect of the disease and the ICD.

Sexual Intimacy

Fear and embarrassment about addressing sexual intimacy issues can

often prevent a return to regular levels of intimacy for ICD partners. Partners who fear that the partner will have an ICD shock during intercourse may believe that sexual activity is too strenuous. Some partners may fear getting shocked by the ICD patient, but this cannot occur. In the event of shock, others generally cannot feel the shock, even if the patient is in very close physical proximity to another person. In general, returning to intimacy is safe and is an important step toward regaining a satisfying lifestyle.

Suggested Strategy 13: Seek Subtle Ways to Become More Intimate

Sometimes getting back to sexual activity may produce feelings of discomfort. Take it slowly, and remember that there are many different ways to be intimate with your partner other than intercourse. Ease back into activities that are comfortable for you and your partner, and communicate your concerns. Remember, although fears related to sexual and physical activity are common, activity is not related to appropriate ICD shock.

Overprotection

Sometimes, in an attempt to protect the patient, a partner may inadvertently prevent the loved one from returning to a full lifestyle.

Suggested Strategy 14: Encourage the Patient to Live Life Fully

Although withdrawing from activity or taking on the patient's responsibilities may seem helpful in the short term, patients report better quality of life when they continue activities that they participated in before receiving an ICD.

Effect on Children

Children (and other family members) may have a difficult time adjusting to and accepting a parent with an ICD. Children may witness ICD shock and be frightened by the experience. They may also have a poor understanding of the device, causing undue worry.

Suggested Strategy 15: Inform Children About Shock and How the ICD Works

Children are often resilient and can handle seemingly difficult information

if it is presented in a nonfrightening manner. For example, when explaining shock, it may be helpful to describe the process as the ICD “resetting the heart.” You may wish to seek further advice from experienced pediatric providers on what level of detail children may need.

Conclusion

Partners of ICD patients may face difficulties on several fronts, including caregiving expectations, learning about the ICD, and managing stress related to the future of living with cardiac disease in the partner. Doctor appointments, health education, and frequent discussions about necessary changes may be an unwanted reminder about your partner’s heart condition. The goal for you and the patient is to achieve a high quality of life because

of the protection that the ICD provides. A good quality of life is obtainable when the patient and the partner, along with the help of friends, family, and healthcare providers, can work as a team. Together, this goal can be reached by adjusting to life with an ICD, avoiding or managing psychological distress, and maintaining healthy relationships and activities.

Disclosures

Dr Sears serves as a consultant to Medtronic and has or has had research grants from Medtronic and St. Jude Medical. Dr Sears also has received speaker honoraria from Medtronic, Boston Scientific, St. Jude Medical, and Biotronik. J.B. Shea serves as a consultant to Medtronic, Boston Scientific, and St. Jude Medical and has received honoraria from Medtronic. The other authors report no conflicts.

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