

IT'S SEX AND MORE: IMPROVING OUTCOMES FOR PARTNERS OF PATIENTS WITH ICDS OR LVADS

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WHAT TO EXPECT TODAY

- Most care happens at home
- A committed other, ie; spouse
- Supports physical/emotional healing but at a price
- This presentation reveals the toll on this person's own physical, emotional and spiritual health and
 - offers recommendations for CNS Support
- Yes, it is sex and more!

CLINICAL NURSE SPECIALISTS' CARE OF CAREGIVERS



WHAT DO THEY DO?

Pre-device

Assist in decision to get device

Post-device

- Assist with physical needs ie., getting urinal, pillows
- Vigilance
- Limit activity to support recovery and prevent shocks
- Provide encouragement
- Drive to appointments
- Presence

WHAT DO THEY DO?

Post-Device

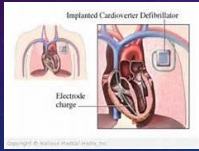
- Help with exercise regimen
- Shift role to more work ie., cooking, shopping, finances, etc.
- Provide emotional support and protect from stressful situations
- Help with treatments and medications
- Manage symptoms

WHAT DO THEY DO UNIQUE TO LVAD

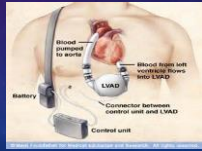
- Assist with basic cares ie., dressing, bathing
- Assist with bedtime routine, a comfortable sleep position
- Monitor blood pressures, medications, weights
- Perform sterile dressing changes, handle battery issues, docking system
- Monitor LVAD function and alarms, back up batteries charged and materials gathered for dressing changes
- Prepare for emergency situations

HOW DO CAREGIVER RESPOND TO THIS TYPE OF CAREGIVING?

Implanted Cardioverter Defibrillator



Left Ventricular Assist Device



NEGATIVE RESPONSES

- Anxiety
- Depression
- Fatigue
- Less time
- More chores
- Post-traumatic stress syndrome



CONCERNS OF CAREGIVERS

- Getting answers
- Not being informed
- Use of professional jargon
- Resorting to call 911
- Lack of attention to self care needs
- Constant worry of infection or malfunction of device



ADJUSTMENTS IN SEXUAL ACTIVITY

- It might cause a shock
- Seeing the patient's scar
- Engage in other intimate acts – hugging, cuddling - less apt to promote a shock
- Relaxation exercises before sex
- Watching the flow and rate of LVAD
- Blame HCPs for not talking about it



POSITIVE RESPONSES

- Better communication with the patient
- More honest and loving relationship with the patient
- Being grateful having a second chance
- Supporting each other
- Security in feeling the device is supporting the patient
- Becoming more lighthearted and optimistic
- Enjoying just today
- Ability to help others in similar situations
- Helping the next generation

GUIDELINES FOR CNS CARE OF CAREGIVERS

- Identify concerns/needs of caregivers at the time when the device is proposed
- Be available in first 3 months (telephone call away)
- Get all HCPs to pay attention to the caregivers
- Reach out, listen, give adequate responses to questions
- Bring up sex!
- Be honest of the realities of the situation

SEXUAL COUNSELING

- Use 'Just Ask' approach, often and across settings
- Checking battery function, monitoring the device
- Modifying positions during sexual activities
- Encourage sex unless there are specific contraindications
- Explore ways to minimize stress on the patient's heart function
- they will not be shocked if the patient is shocked during sex

END OF LIFE CARE

- Include the Caregiver in these discussions
- Peaceful death experience versus shocks to the body
- Death of other causes and deactivating the device

MORE RESEARCH

- Select and test out interventions for caregivers
- Investigate differences for race/ethnicity, gender, level of education, employed or not
- Assess both quality and cost-related type outcomes
- Use of 24/7 on call services
- Performing more complex cares - no current payment system that subsidizes these cares

AMERICAN HEART ASSOCIATION WEB-SITE



CONCLUDING REMARKS

Caregivers provide the needed support patients need at home
Caregiver assessments
Be supportive of their needs
More research

Thank you!
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