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Minding Our Elders: Spousal caregiving can be isolating

DEAR CAROL: My wife has advanced Parkinson's complicated by dementia and needs constant care. She's mostly bedridden. I love her dearly, and we've spent considerable time talking about our past vacations and other enjoyable things we've shared. We have no children. As much as I love her, I'm finding myself becoming extremely lonely and isolated as she becomes less and less able to communicate.

By: **Carol Bradley Bursack**, INFORUM

DEAR CAROL: My wife has advanced Parkinson's complicated by dementia and needs constant care. She's mostly bedridden. I love her dearly, and we've spent considerable time talking about our past vacations and other enjoyable things we've shared. We have no children. As much as I love her, I'm finding myself becoming extremely lonely and isolated as she becomes less and less able to communicate. While we don't have a lot of money, we are comfortable. Hiring in-home caregivers will be costly and I don't know if I can trust them. Yet I know I should get out more. Where do I draw the line and start creating a life apart from my wife's illness. – David

DEAR DAVID: You must start creating a life apart from your wife now. In many ways you've been very fortunate because you've had this loving partner with whom you seem to have shared nearly everything. However, her life is draining away. While your life is diminished by her illness, you owe it to yourself and to her to make the most of what you have.

If you belong to a church, you might want to inquire about the Stephen Ministry. Stephen Ministers are lay ministers trained to work with situations like yours. Even without an organized group, there may be people from your church or synagogue who could provide you with respite care so that you can go out knowing your wife is in safe hands.

Another route to finding support is to type the name of your state and the word "aging" into your web browser. By doing so, you should find your state's version of the National Family Caregiver Support Program. It may have a slightly different name, but every state has the program. Use the contact information that is given to search for respite care so you can get some time for yourself. Of course, there are many good agencies that provide in-home care. It's costly, but this care often provides a bridge toward accepting more intensive help.

The main concern here is that you need to have time to yourself so that you can begin to build a life outside of that with your wife and her heartbreaking illnesses. Doing so doesn't mean that you are giving up on her or neglecting her. It simply means that you value life enough to do what you can to improve your circumstances.

It's possible that even if you arrange a few daily hours of respite care, this will not suffice for long. You need to be able to sleep at night and not constantly worry about your wife. Start asking your friends about local nursing homes. Many of the best facilities are full, but you can place your wife's name on a list. When your wife becomes a resident of a nursing home, you are still part of her caregiving team, but you'll have badly needed help.

You are only human. If you are lonely and worn out from providing her care, you will not be able to give her your best efforts. So, for both of your sakes, please follow through. Break your isolation, contact agencies and start looking for outside help. She would want you to have a life outside of her constricted world.

Carol Bradley Bursack is the author of a support book on caregiving and runs a website supporting caregivers at www.mindingourelders.com. She can be reached at carol@mindingourelders.com.

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