

SUPPORTING YOUR SPOUSE(AND YOURSELF)

BY DEBRA ROONEY

Spouses and significant others of new ostomy patients can often feel frightened, worried or left out of the process. Because bowel and bladder cancers tend to strike later in life, older spouses often find themselves in the position of dealing not only with the emotional and physical aftermath of ostomy surgery, but with a loved one's cancer diagnosis as well. It can seem like all the resources are devoted to the patient and the husband or wife is reduced to being an anxious bystander – wanting to help but unsure how and in need of support themselves. How can you help your partner and take care of yourself at the same time?

ASK QUESTIONS

Don't be shy about asking the doctors and nurses questions! Make a list of the things you may be worried about, such as:

- How soon can my spouse leave hospital?
- Will home care be available and for how long? How will this be set up and what contact numbers do I need? Is there a charge for home care?
- Will my spouse need to take any new medications?
- Does my spouse have to follow a special diet now?
- Where is the nearest outlet where I can purchase ostomy supplies?
- What cancer/ostomy support groups are available for my spouse after recovery?
- What support groups are available for ME?

Take the opportunity to ask your questions when you see your spouse's doctor, and especially their ET nurse. If you can, keep a notebook and write down the answers you get. Compile a list of contact numbers in the same notebook so everything is handy when you need to make or confirm appointments, i.e: the doctor's office, the ET office, home care or the BC provincial Cancer Agency.

HELPING CARE FOR THE OSTOMY

Ask to be present when the ET nurse begins instructing your spouse on how to apply and change their ostomy products and don't hesitate to ask to have something explained if you're puzzled. If you understand the process you can help your spouse later at home if they forget steps or are nervous about handling things alone in the beginning. However, assisting your spouse should NOT become a constant habit. Unless there is a very good reason for it, letting your husband or wife become dependent on you to maintain hygiene is not doing them any favours. There are valid reasons for giving your spouse ongoing assistance such as: eyesight so poor they cannot see the stoma area clearly, hand tremors so severe they cannot apply the pouch, or memory impairment that makes it difficult to remember procedures, are all reasons for helping your spouse change their appliance.

Fortunately, very few spouses are so dependent on their mate that they would want them to help change their appliance all the time. While your loved one is learning the ropes, offer to be on standby to fetch or hand them something if needed.

Read any ostomy pamphlets, books and product advertising you can find or ask for literature on the subject – the more knowledgeable you are on the subject, the better.

It's not unusual to have a few leaks and accidents in the beginning and sometimes some skin irritation will occur. These things can and should be resolved either with practice or consultation with an ET nurse. Chronic skin irritation or leakage is not normal however and your spouse should not be putting up with such discomfort. Make sure they seek help if they're having problems. Don't let them try to "tough it out" out of pride or embarrassment.

EMOTIONAL SUPPORT

Your spouse may recover quickly from surgery and resume their previous activities at a surprising rate. Others may take more time to regain confidence – give them time to sort things out. There is no set timetable for when and how new ostomates begin to socialize again or resume previous interests. You are probably the best judge of your spouse's behaviour and can tell the difference between understandable withdrawal at a bad time or the symptoms of serious depression and unhealthy avoidance. A certain amount of withdrawal is normal as are tears and anger but prolonged behaviours of this sort for weeks or months is a sign that your loved one may need more help moving forward. Encourage them to seek out and speak with other ostomates who have the same type of surgery and if possible, the same diagnosis. Sometimes just seeing another person who has reclaimed their life despite the ostomy is enough to inspire renewed determination.

TAKING CARE OF YOURSELF

This is a stressful time for you, too. With so much going on, don't forget that you need to look after yourself as well. Make time to get out of the house and have a little "you" time – playing a sport, a little drive somewhere, coffee with the girls (or boys) – in short, whatever you usually did before the health crisis hit. Some spouses exhaust themselves trying to do everything and thinking they mustn't leave their partner alone for a minute lest they need something. Your spouse needs some "alone" time too. Give yourself permission to re-charge your batteries from time to time.

Sometimes a spouse may have to be in hospital for a prolonged period of time. If you are spending long hours keeping them company, don't neglect your own nutrition and need for rest or exercise. Get other family members and friends to share the visiting load and give you a break. And don't be afraid to ask for favours – people want to give help during times of worry so if asked if there is anything someone can do, accept the offer of a lift somewhere, or a meal you don't have to cook. Or just a friendly ear to listen.

TALK TO OTHERS WHO HAVE BEEN THROUGH IT, TOO

Some UOA "United Ostomy Association" (now "Ostomy Canada") chapters across Canada have affiliated SASO groups (Spouses and Significant Others) who may be contacted for support and encouragement. If no SASO group is present in your area, contact the local "Ostomy Canada" main chapter who will put you in touch with a husband or wife who will be happy to listen and share their experiences with you.

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