Mind, Body & Soul Mirror, Mirror on the Wall... How Can I Love My Body Again?

By Robin Siegal, LCSW

"I can't fit easily into my pants anymore..."

"I feel bloated a lot and hate feeling like I'm pregnant – especially because I'm a guy..."

"How could my partner ever want to be intimate with me again when I have this plastic tube sticking out of me..."

These statements and other concerns are often expressed by individuals on peritoneal dialysis (PD), a form of renal replacement therapy that uses a patient's peritoneum in the abdomen as a membrane which filters toxins. As a long-time psychotherapist and renal social worker, I have had an interest in issues related to body image, sexuality and intimate relationships. I have travelled throughout the United States, speaking about my research and experiences to social workers, nurses and doctors. In addition, I have been fortunate to listen to the stories of renal patients and their loved ones address these sensitive issues.

Throughout this article, I'll address issues related to body image and sexuality. I'll provide some challenges to think about with some guidance and solutions in navigating these feelings that are common to individuals on PD.

First, you MUST speak with people about your feelings and thoughts about the PD experience! This not only includes your family and intimate partner, but also taking the initiative with your health care team - your doctor, nurses and social worker. It always seemed ironic to me that one can discuss their bowel movements so freely to their physician, yet be hesitant to discuss body image and sexuality. The reality of the situation is - you have to initiate these discussions, because studies have shown how very few medical professionals do.

These discussions might start with you asking questions during your regular appointment, then making a longer appointment for a follow up. Begin by asking questions - a lot if necessary. This way you are effectively communicating

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your concerns about your treatment and can explore different options on how to deal with them. Initiating these discussions with your medical providers will allow them to understand your concerns and help you find reasonable solutions. Don't be afraid to ask for further explanations if needed, you are the consumer and are entitled to all the best education about your treatment. Studies have also shown that people who take an interest in educating themselves about their medical conditions and treatment often have better outcomes with their care.

Second: Many of your feelings and thoughts will change over time. Your initial physical and psychological reactions to PD will shift, as you and your body become more accustomed to this treatment option. For example, during the first several months, it is quite common for people to experience a bloated sensation, as their muscles become adjusted to



holding the dialysate in their bodies. Report and discuss any of these symptoms with your medical team if they concern you.

Third: Find the right people to speak with. Speaking with others on PD will help enormously. Ask your medical team if there is someone in your clinic who can give permission (due to privacy laws) to speak with you directly. Find other patients who have been active and involved with their care and have successfully found "the right balance" in their treatment and obtaining their desired lifestyle.

You may be interested in asking your social worker if you can start an educational forum to address these topics or create a newsletter in your clinic by having people write about their solutions to PD challenges. From my discussions with patients and their intimate partners, I have heard many ways people have been able to deal with changes in their body and

> intimate relations. For example, hiding the catheter in a bathing suit, how to calm fears associated with having sexual relations, worries about "harm" that might occur to a PD catheter from being intimate.

Here are some challenges and solutions to explore that are common to many PD patients:

What is body image? It is the mental picture that people have about their own bodies and bodily functions. It also includes your personal perception of the way others see you. A permanent peritoneal catheter, distended abdomen, scars, uremic breath can contribute to feelings of frustration or anger. Sharing your personal experiences with others will help you normalize your feelings, find support and arrive at solutions.

Start getting active again! Beginning a simple exercise program will help improve your feelings of wellness, but will also improve your muscles, flexibility and cardiac condition. There are numerous benefits from exercise. Feeling stronger and developing a feeling of "body strength and ability," will enhance your body image, improve your emotions and make you more likely to engage in relations with others. In addition, there are some exercises you can discuss with your health care team, whereby you can strengthen your stomach muscles. This can potentially help with hernias, a distended abdomen or strengthening your back.

Examine your clothing options. Initially, many people on PD like to wear clothing with elastic waistbands where they can feel more comfortable. One needn't spend lots of money to obtain a new wardrobe. Altering existing clothes and buying from thrift shops can be inexpensive solutions. Often these are temporary experiences while your body adjusts to this form of treatment and you may be able to resume wearing your previous clothing after a few months.

I feel pretty or handsome. Maintaining your appearance is important while being on any form of dialysis. Dental hygiene, good bathing practices, wearing a special cologne or perfume helps you maintain your special identity with others. Wearing clothing that helps you feel attractive, getting your hair styled, manicures/ pedicures, etc. will add to your positive body image and self-identity. You are worth the fuss! Don't allow yourself to become a "professional patient" use your time to also explore ways of feeling attractive.

Romance your sensuality. Engage in activities that enliven all your five senses such as listening to beautiful music; smelling lovely fragrances; observing things of beauty; tasting delicious foods; and giving and receiving a massage. These are things that make life worth living! Don't deny yourself and your partner these various activities. They will help you re-discover your sensuality and sexuality. Make this a "new project" with your partner and loved ones.

Where to place the catheter? Many people have various forms of keeping the catheter on their bodies while dressed: tape and gauze, having little "pouches" in their clothing to hold the catheter, a catheter belt or even placing it inside their bra!

Placing the catheter while having sex is also a challenge many face. Some people find talking with their partner about their concerns is important, as their partner may worry they will "hurt the catheter" while engaging in sexual activity. Discuss these concerns with your doctor or nurse, as they will provide helpful advice and

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guidance. It is also necessary to discuss sexual activity when using a PD cycler at night. Some people find that disconnecting the catheter from the machine between cycles is best, while others engage in sexual activity without disconnecting - yet securing the catheter safely. Also, finding various times in the day when you have more energy is important. You may find that when you schedule sexual activity, you are more open to other times of the day: with or without a cycler, having fluid in or "being dry."

Think of others! It is easy to fall into a cycle of focusing all your attention on yourself while on dialysis. Make sure that you are aware of the people around you by showing them affection, speaking kind words, writing cards or buying flowers. Pushing yourself to go on a date even when you may initially not feel up to it. Seeing a movie, going to the park, taking a special weekend or day trip can provide enormous possibilities for engaging with your partner or family members. It is a way of reclaiming all the aspects of yourself - all the things people love about you!

Don't forget to express appreciation for your loved ones. It's not enough to say to yourself "they know how I feel, I don't need to say it"- express it openly by your words and actions. Improve your communications, demonstrate gratitude for those around you and improve your "lovable-self."

Finally- Have a good sense of humor! An old poster of mine said, "*Don't take yourself too seriously*." Being able to laugh at oneself and finding the humor in life's challenges is so important. It is what makes life so rewarding. People will enjoy being around you and will find you attractive simply by being friendly, humorous and open to possibilities. You can still be serious about your medical care and enjoy your life with others.

These simple actions will help you reclaim your identity and redefine yourself as a person living happily on PD. Share your life fully with others. *Enjoy the journey*.



Robin Siegal, LCSW, is a published author, maintaining an active private practice and speaking schedule throughout the United States. Robin is known

for her sense of humor, boundless energy, engaging and thoughtful presentations. Ms. Siegal is active within the renal community, creating cutting-edge programs for local renal support groups.