

## ***How SASO Came To Be***

Where does one start a story? When asked to do this by the Ostomy Canada editor, I had no idea what I would do. All Janet asked is if I could write an article on how the Spouses and Significant Others became part of the UOAC organization. Like everything else, necessity is the mother of invention.

My husband Mike was diagnosed with colo-rectal cancer in 1992, the only other person we knew with this kind of cancer was Mike's mother, who died three weeks after surgery. Shock, disbelief and anger – all these emotions were going on within us. Where do you turn to for some guidance? Both our families were very supportive, but like us they too remembered what Mike's mother had gone through. As for a support group like UOAC, we had never heard of it. It would have been an asset to us at the time if we had.

Mike was so sure that the end of the road had come for him. He was getting everything in order so I would be secure after he was gone. We talked to the surgeon. After hearing Mike's family history with cancer, starting with a younger sister, she was 15 years old, six years later his father died of cancer and 10 years later his mother. He told us there were no guarantees but he was hopeful. I think that was the day I said "Enough of this doom and gloom, we are going to be positive about this, we are going to beat it. Today's technology is so much better than it was when your mother died."

The day of his surgery I was waiting by his room for him to come out of recovery. A very nice nurse about my age came to see if she could get me anything. I just wanted to ask some questions about life after surgery. Her answer was "I don't know anything about colostomy surgery; I just know how to care for wounds." If only there had been a support group around at the time and someone for me to sit and talk to, someone who had been down this same road before me.

A few days later when I returned home from the hospital, there was a message on our answering machine from an acquaintance asking me to call her. She had filled in at the bridge club for me that day and had just heard about Mike's surgery. I called her back and she told me her husband had the same operation four years previously. (Her husband's cancer had returned and was terminal.) She told me that if there was anything either one of them could do to be of any help we were to call them. I thought it was very brave and sweet of her to call and offer assistance when they were going through such turmoil themselves. Of course, I kept Mike from meeting them because I didn't want him to be discouraged by their news. How wrong I was.

The hospital had no ET nurse on staff and a few days before Mike was released I was told by the hospital that I had to take him to another hospital in downtown Vancouver for equipment training and supplies. I had never driven in downtown Vancouver, so a friend of mine who was a doctor on staff at the hospital drew me a map of how to get there quickly and safely. The day before Mike was released, our son from Cold Lake, AB and daughter from Halifax, NS and I did a trial run down to the hospital.

The day of Mike's release arrived and off to the downtown hospital we went. When we arrived, there was no ET nurse. She was on vacation and nobody from the hospital had called to confirm that someone would be available to see him. Angels come in many disguises. The receptionist at the out-patient clinic took one look at Mike, found him a room and said she would have a nurse who was hoping to someday become an ET see him. She often helped the ET on staff with her clinics. This nurse took us into a bathroom and showed us how to apply the flange and secure the pouch. (This was my first time seeing his stoma). She ordered supplies for us and had them delivered to the hospital 'pdq'. She then helped us to locate a supply drug store near us in Richmond BC where I could go with his prescription to get his supplies.

We went home to the routine every ostomate and their family go home to, rounds of chemotherapy and radiation. Learning how to cope with this change and trial and error are your companions. Wouldn't it have been nice to call someone just to ask some questions on everyday living with an ostomate? Some of the mistakes I made with menu and cleaning of clothes would have been so much easier having someone there just to say use this brand of stain remover it works better than that brand, or, that vegetable is so much gassier than this one.

About four months later Mike had a terrible time with his appliance, it wouldn't stay on. Who did we call? We never did see the ET nurse or even know her name. As for a chapter of UOA Inc. (as it was known at that time) we never knew it existed. Mike said "Call the lady who filled in for you at bridge see how her husband is and if he is not too sick, maybe we can go and see him and he can advise me how to deal with this problem." I called her; both she and her husband were delighted to have us come for a visit.

This man who knew his days were numbered was another "Angel" to us; he gave us the name of the ET nurse at St. Paul's hospital and also an old newsletter from the Vancouver chapter. He advised us to join and said that we didn't ever have to go to a meeting if we didn't want to but the information in the newsletter was invaluable.

We contacted the ET the next day and Mike was in to see her very quickly. She told him what was wrong and how to fix it. That was 15 years ago and Mike has not seen an ET since in a professional capacity. We filled out the application for membership into the chapter so we could receive the newsletters.

Mike returned to work February 1<sup>st</sup> 1993. As he was in the airline industry and travelling all over the world, his first trip out was to South America. I don't know who was most scared, me or him. As I was always there to help with the changing of the appliance I could not and would not travel all over with him so he had to learn to do everything on his own. I guess one of the things some of us tend to do is baby our spouses, especially after the children leave the nest. He had to change the appliance sometime while in South America and from that day to this I have not been anywhere near him while he is changing his appliance.

It was March or April when he decided that he would like attend a meeting of the chapter. It almost didn't happen. On our drive into the meeting, his stoma decided to become active. He went into the washroom when we arrived, came out and said "Let's go home. I'm afraid this thing will get too

active.” Being the optimist, I said “We are here: Let's see what they're all about.” Well. I think you can count on one hand how many meetings he has missed since then. As for the spouse there was no one, or any contact for them. You just tagged along hoping you would meet someone like yourself, someone living with a spouse or loved one who is an ostomate. I met a few and they all seemed to have come through the ordeal the same as me, one day at a time and a lot of prayers.

About a year later, I took a call from the President of the chapter asking if she could give my name and telephone number to a spouse who was having a hard time dealing with all that had happened to her in the last six months, her spouse's ostomy surgery, etc. ... she called me and we talked for about an hour, all she needed was to know that she was not alone with her feelings and that most people who go through this have feelings of one kind or another. I hoped that I helped her in some way.

Shortly after we retired back east, arriving in Halifax two years after surgery, we quickly became members of the local chapter. There was still nothing for spouses as a one-on-one contact. At the 1998 UOAC conference in Mississauga, while walking to lunch one day, I proposed this question to an ostomate, “If your spouse or one of your children had to have ostomy surgery, how would you handle it, being an ostomate yourself?” She stopped dead in her tracks and looked at me in shock. Her reply was “I don't know what I would do, or how I would handle it. I have just never thought of being the spouse or mother of an ostomate.” I made up my mind there and then that something was going to be done about it, at least at the chapter level. I contacted spouses, parents and some partners. We had a meeting in one of the homes in Halifax. The consensus was that we do need something for the spouses, parents and partners of ostomates. I then went to other chapters in the Atlantic region with the same questions and received the same answers. I approached the National President in May 2000 about this idea. He thought it was pretty good.

I was asked to make a presentation at the spouses' session at the 2000 conference in Montreal with Jack Okun. I met with Jack about ten minutes before we were to make our presentation and give him my idea. Both Jack and Bertha thought it was a very good one and both applauded, saying “The ball is in your court, go for it!” I made the presentation and it was well received. I then had to go through the national body. It was about mid-December when I received a call from the National President asking if I would sit on a committee. I was delighted to do so.

I flew to Toronto on June 2001 and met with Louise Aronson and Ann Ivoll, two ladies I had never met although we all had attended the same conferences. We discussed how we were going to go about forming this group and what our goals would be. We chose the name “Spouses and Significant Others”, SASO for short. This title would include everyone from spouse to friend. We had a bit of a contest to select a symbol and we presented this information to the National Board at the August Conference held in Vancouver. This is where we held the very first session of SASO. If I remember correctly, there were about 7 people who attended our meeting and about 15 at our discussion session.

My expectation of SASO is that we are there to support spouses, partners, parents, etc. when they have a day that is not the norm. They could call a SASO number and just vent. Remember, spouses can be just as traumatized as the ostomate. When our spouse or significant other has a bad day it is us who goes through his frustration with them. We must let our frustrations out somewhere and we can't or won't let it be onto our loved ostomate. The spouse can then comfort their loved one

without harbouring any bad feeling about what upset the ostomate.

***We are not here to get a pat on the back for what we do;  
we do what we have to do for love.***

There was a lot of work done that year. We wanted to be ready for the 2002 conference being held in Halifax and we wanted more people to attend the SASO meeting. We had created quite a lot of interest with the spouses who had attended the conference in Vancouver.

During the conference in Halifax, we were recognized as a viable part of UOAC. This made us very happy. We are not here to help the ostomate one-on-one, but to help their spouse, partner, parent or family member or a friend who just wants to help the ostomate make the adjustment he or she needs to make. There are cases where the ostomate is fine with adjusting but the spouse or partner has some difficulty with the adjustment. One of the main questions we get all the time is "Do I have to change their appliances for them?" We always encourage the partner not to, unless there is a valid impairment in the ostomate such as blindness or very arthritic hands. I always ask "Did you go to the bathroom with them before the surgery?" Of course the answer is an emphatic NO. "So why should you go with them after they have had their surgery?"

Every person is different and we treat them as they should be treated, with comfort and dignity. Privacy is a very important part of our group, the same as it is for the ostomate.

I was fortunate to receive the highest award this year at the conference held in Calgary, the Maple Leaf Award. I am very proud and grateful for this honour, but it must be shared with all the SASO members in the UOAC organization. Without them we would not be a part of UOAC, especially Louise Aronson and Ann Ivov who worked tirelessly to get where we are today. If we have helped one person on this road called life with an ostomate then we have done a very good job.

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