

CAREGIVERS:
HINTS,
HELP
&
INFORMATION
FOR
US

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FOR CAREGIVERS
TABLE OF CONTENTS

	Page
HOPE	
Hope, a short essay.....	3
No Evidence of Disease (NED); a patient’s story.....	4
Managing Kidney Cancer; a patient’s story.....	6
My Caregiver Journey, Karen.....	8
HELPFUL HINTS	
Hints for Caregivers.....	11
Financial Tips.....	13
Caregiver’s Emergency Bag.....	15
How to Help the Hospitalized Patient.....	17
How Friends Can Help.....	18
CAREGIVER NOTES FROM ASCO PRESENTATIONS	
American Society of Clinical Oncologists (ASCO) notes 2010.....	20
RESOURCES	
Books.....	22
Websites and Videos.....	23

HOPE

Hope is not a constant. It is always changing with the situation and the people involved. Hope is what keeps us going when we are scared, when we are worried or when we are bone tired. Hope is what allows us to accomplish super human feats when it comes to protecting or helping someone that we love.

Hope gives us something to strive for, to work towards, to accomplish. At the end of the day it is sometimes the only thing that gets us through the day.

Hope can be for something big or small. We need to acknowledge even the smallest hopes and victories to help us to continue on. Perhaps hope is for a surgery to go well, for a blood transfusion to take, for blood counts to be good enough to get the next course of medicine, for the Imodium to work, for a day without needles, for stability or even just for a glimpse of sunshine.

In the not so distant past, a diagnosis of kidney cancer was pretty grim. After the radical nephrectomy, Interferon and High Dose Interleukin II were the only treatments available then. HDILII was given in Montreal and in the US and was not really recommended by too many doctors because of the intensity of the side effects. Both these drugs had a low response rate. There was little reason for hope.

Since 2005, targeted drug therapies have taken the kidney cancer world by storm and are offering patients hope. These drugs might result in shrinkage of tumours, achieve stability, be able to manage the cancer for long periods of time, or might, with the combination of other interventions, even achieve “NED” (no evidence of disease). Here is a reason for hope, a hope that gives the patient the ability to plan, to look to the future, and to know that there might be a future.



NO EVIDENCE OF DISEASE: A Patient's Story



Diane Porter lives alone with her cat Murphy and is greatly involved in the community. In 2008, she was awarded “Volunteer of the Year” in Fredericton. She is well known, respected and loved in the city, with many friends.

She was the wife of a firefighter, the mother of three daughters and one son. In 1974, her daughter got married, her only son died in June, and her husband was killed in a work related accident in October. That year there were three gone from the Christmas table.

Diane was employed by the local hospital in Fredericton in security and devoted 22 years to helping people in the medical world. She retired in 1995.

In 1997, Diane had sudden high blood pressure problems but no other symptoms. Her family doctor told her that he learned in medical school that when a patient experiences high blood pressure problems that hadn't been present before, the kidney should be checked. An ultrasound revealed a small contained tumour in the left kidney. 10 days later, Diane had a radical

nephrectomy which included removing the tubes going to the bladder. She remained in the hospital for 9 days.

3 months later Diane was wallpapering her kitchen. She told her doctor, “It would take more than that to keep me down”. In 2010, she is presently a 14 year kidney cancer survivor. Scans every 6 months for 5 years, and then every year after that continue to show no evidence of disease (NED).

In 2001, Diane was diagnosed with breast cancer, as another primary cancer, with 6 lymph nodes involved. She underwent a radical mastectomy, 12 weeks of chemotherapy and 16 weeks of radiation. She had a mammogram every 6 months for awhile and then once a year. In 2010 she is a 9 year breast cancer survivor.

Throughout the years Diane helped organize the cancer support group in Fredericton; she is a volunteer for her church which is responsible for the Chapel services at the local hospital every Sunday; she is a very busy volunteer for the Canadian Cancer Society and she is a member of Kidney Cancer Canada. These are just a few of the many ways she gives her time to help her community.

ADDITIONAL RESOURCES:

www.kidneycancercanada.ca RESOURCES - KIDNEY CANCER TREATMENT GUIDELINES (Canadian)

www.kidneycancercanada.ca ABOUT US – PATIENT AND CAREGIVER VIDEOS

www.kidneycancercanada.ca ABOUT US – PATIENT STORIES



MANAGING KIDNEY CANCER; A patient's story



In the year 2000, David was a healthy, active man of 55 and going strong. He had lost 65 pounds intentionally and kept it off, was exercising daily and did not need his diabetes medication any longer. All David had to deal with over the years health-wise were two sessions of kidney stones, minor bladder surgery and the usual colds, flu and diabetes.

Why were we so shocked? Looking back it must have been denial and the innocence that comes with an uneventful health situation. David had three risk factors on the list. He had been overweight for most of his adult life, he had been subjected to second-hand smoke from birth and he had worked in a smoke-filled atmosphere for over 25 years. Both his parents had kidney cancer, his Mom in the 60's and his Dad in the 80's, before new advances were discovered to help patients.

David was diagnosed in August 2000 with clear cell renal cell carcinoma and had an extremely difficult radical nephrectomy within one week of diagnosis, performed by a wonderful urologist Dr. Donald MacQuarrie who has since retired and Dr. Claus Schaus, an excellent vascular surgeon. There was no sign of the cancer having spread before the operation and the pathology report stated that the margins were clear.

The next two and a half years were full of concern and hope. Only chest x-rays were done because the lungs were supposed to be the most obvious place for kidney cancer to recur. Standard of care for kidney cancer has changed greatly in recent years with the advent of new treatments and information.* [See - Resources/Kidney Cancer Guidelines on the KCC website](#)

In 2003, David was diagnosed with a recurrence in the kidney bed cavity, (about 2% of kidney cancer patients have recurrence in this area). By the time that was discovered, it was deemed inoperable and he was prescribed Interferon; subcutaneous self-injections 3 times a week. Interferon rendered him so fatigued that he did not even have the energy to eat properly or move around the house. Visiting an urologist in 2003, Dr. Mike Malone, at the Lahey Clinic in Boston, we were advised that a debulking surgery would be appropriate followed by a return to Interferon to try to shrink the remaining tumour. Two wonderful Canadian surgeons, Dr. Peter Feero (urologist) and Dr. Claus Schaus (vascular surgeon) performed a very intricate surgery and their combined skills aided them to remove the entire tumour. The cancer has never returned to that site as of 2011.

Unfortunately, inoperable metastases to the liver were discovered in 2004. Another trip to the U.S. led to David having High Dose Interleukin II at the Beth Israel Deaconess Medical Center in Boston but he did not respond.

On October 3rd, 2005, David started Sutent under Dr. Lori Wood, an exceptional medical oncologist in Halifax who specializes in kidney cancer and the liver metastases have been controlled ever since. In 2009 David developed mets to the bone marrow of the spine at the T2 level and underwent radiation with an excellent radiation oncologist, Dr. John Carson in Saint John, New Brunswick. In 2010 he had an embolization and a kyphoplasty to fill the hollow vertebra in order to avoid a collapse of the vertebra. This was performed by an excellent orthopaedic surgeon, Dr. Neil Manson in Saint John, New Brunswick.

David is a classic example of a person managing his kidney cancer. He relies heavily on his medical team to get him through each event. David bikes and walks for exercise every day and attends Search and Rescue activities when the weather permits. He leads a good life.

It will be 11 years August 3rd, 2011, that we have been on our cancer journey and we have learned what it truly means to manage one's cancer.

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My Caregiver Journey – Karen

My journey started in 2000 when David (age 55) came home from a bike ride and told me there was blood in his urine. By the time we got it together and started for Emerge, he began to have pain in his side. We weren't too concerned because this had happened before when he had kidney stones.

I can still remember feeling a hot, searing rush of heat roar through my body when he told me that the doctor said that he had kidney cancer. We spent the rest of that day in the living room, crying, thinking and talking. The next couple of days went by in a blur of numbness. Tears were always right near the surface, ready to overflow – they didn't seem to need a trigger. Sometimes we cried together, totally exhausted trying to keep up a good front for each other.

It was equally hard to tell our adult children what was in store for David and we only had a couple of days to digest it all. Remember, this was the year 2000, and the prognosis for kidney cancer patients was pretty grim. Fortunately, since 2005 with the advent of targeted drug therapies there are options and hope.

During David's radical nephrectomy, family and friends were in the waiting room with me, and I felt like I was having an "out-of-body" experience; hovering over the room, looking down at everyone as if they were on a TV screen – it was as if it wasn't happening to us. That must have been my mind's way of helping me cope. It was a very difficult surgery as we all knew it would be but it was even worse than we could have imagined. The miracle was that the doctors' hands were guided through an extremely challenging day of surgery.

A wise nurse told me in the hospital corridor during my first meltdown "Don't think of tomorrow, let's just help him get through today" and that seemed to put things in perspective for me and helped me to move forward as a caregiver.

When David went on Interferon in 2003 for a recurrence in the kidney bed cavity, it was to be administered by self-injection. We decided that David would do the injections and I would prepare the needles. The representative from the VON (Victorian Order of Nurses) came to the house to teach us how to prepare and self-inject the needles. I remember being so fearful that I would make a mistake. Having so little confidence in myself, it was almost paralyzing. The nurse understood and came back to help me 3 or 4 times until I gained enough confidence to do it myself. David was on Interferon for 4 months but he did not respond.

The second surgery, in 2003, following the Interferon was equally unnerving. We went into this one a little wiser but still very nervous because of our experience with the previous surgery. Waiting in the cold, bare halls of the surgical unit on the hard backed chairs for 5 hours seemed like forever. I wasn't fooled when a medical attendant carried his cooler past me on two separate occasions, I knew it

wasn't his lunch. However, the surgery went extremely well and we looked forward to the next phase with cautious optimism.

In 2004, David was diagnosed with inoperable metastases to the liver. This was the point where we went to Boston to the Beth Israel Deaconess Medical Center for High Dose Interleukin II treatment. He was able to have 22 of the 28 infusions. This was an exhausting, scary time for us. The treatment is very intense and is done in an intensive care situation. The staff were excellent but I could not help being concerned for David and hopeful that this treatment would give him more time. Unfortunately David was among those who did not respond to the ILII.

This still left the liver mets to be tended. From Boston we were referred to a Dr. Ko at Sunnybrook in Toronto, who was able to refer us to Dr. Lori Wood in Halifax who had the Sutent trial up and running and we have been with her ever since. Finally we were able to relax a bit, knowing that our doctor was a kidney cancer specialist and was up to date in the latest research and treatment options as well as clinical trials available.

We go to Halifax every 6 weeks now and we try to make the trip into a pleasant experience. Ct scan result appointments are always more intense. David doesn't talk too much and I tend to tighten up inside. It takes me about 3 hours after the appointment until I feel my shoulders relaxing a bit at a time as we drive home to Fredericton. We seem to live in 3 month intervals as I am sure you can all relate.

At the time of writing this article, spring 2011, David is on Sutent and has been for 5 ½ years. He has had several other interventions but we have learned to look at them with a more experienced eye, knowing that we are doing the best that we can and that we have the best kidney cancer specialist for us. Life is good and this gives us strength to face whatever comes our way; but it took us awhile to get to this place.

Being a caregiver can be very frustrating when dealing with paperwork, reports, tests and treatments. The number of things that can go wrong or delay the process is mind boggling; fax machines that don't work, forms get placed in the wrong pile, requisitions don't match what the doctor ordered, requisitions were never received, the doctor is away, the creatinine level is too high – come back tomorrow, the CT IV tube blew – come back tomorrow, oh, and don't forget to drink another full prep of gastrographen as well, and the list goes on. It is a full time job staying on top of things and doing follow-ups to avoid time lost.

A caregiver goes through a whole gamut of emotions, love, empathy, hope, sorrow, pain, guilt, anger, frustration and acceptance. I went to an excellent oncology social worker and she helped me work through my emotions. She showed me how it was okay to feel this way and she also taught me about

anticipatory grieving. Cancer Connections defines anticipatory grieving as “an emotional reaction to loss that you know will occur, but has not yet occurred. Anticipatory grieving is a normal reaction to impending loss. It’s how people learn to cope with the extended care and the eventual loss of a loved one. Learning to live with an impending loss on a daily basis can be one of the greatest challenges the carer will ever face.”

At times, we still share tears with our children, relatives and friends, but we have laughed with them more than we have cried with them. And that is a gift that we choose to give ourselves and them. David’s favourite saying is “Everyday is a good day.”

The same VON nurse that taught me how to make up the needles advised us to try not to dwell on it and allow sadness about the cancer to take over our lives or we would lose the days that we do have to sorrow and not give them to living. To date, David and I have had approximately 3,850 days since the diagnosis and we have chosen to live every one of them regardless of what they bring.

Additional Resources:

<http://www.cancerconnections.com>



HINTS FOR CAREGIVERS

A caregiver should use all the help available to make life easier for the patient and oneself during a difficult time.

The following are a few hints to help:

- ❖ Form a working relationship with the Pharmacists as they are an integral part of the patient's team. In several provinces the Pharmacists are now licensed to do much more so they may be able to solve a drug problem if the doctor cannot be reached.
- ❖ Always go to the same Pharmacy if possible and have all drugs recorded that the patient is taking that did not come from that pharmacy, i.e. if the patient is on a clinical trial, or drugs were ordered at another pharmacy, etc. It is important for the Pharmacist to have this information on file in order to assess compatibility of other drugs that may be prescribed or bought over the counter.
- ❖ Always check with the Pharmacist before buying over the counter drugs to ensure they are compatible with the drugs the patient is currently taking.
- ❖ Form a working relationship with the doctor's administrative assistant. The time may come when extra help is needed. Showing appreciation for all they do may prove to be a benefit to the patient.
- ❖ Always remember that when stressed and frustrated with things going wrong that honey catches more flies than vinegar. Try to stay calm. If the reasonable route does not work another tactic may need to be taken, but always try first.
- ❖ Always do follow-up phone calls if it is taking too long for results to come in or phone calls for appointments are not happening in a timely fashion. It could be an honest hold up or it could be something as simple as the paper got filed in the wrong pile and did not get tended; the fax machine was broken down or the file was misplaced.
- ❖ Start a file of blood test results and scanning reports. Go over them after the appointment when there is less stress involved and there is more time to think. They can also help compose questions for the next doctor's appointment. If there are any areas of concern or misunderstanding, compose questions for the next doctor's appointment. On the Kidney Cancer Canada website under RESOURCES/PATIENT RESOURCES there is an article that will help with medical terms titled *Kidney Cancer Glossary of Terms*.

- ❖ Prepare and record questions for the doctor's appointment in advance. There is a good article on the KCC website that might help titled *Questions to Ask Your Doctor* under Patient Resources.
- ❖ Have a written list of what needs to be discussed with the doctor. If it is going to take longer than a regularly scheduled appointment let the administrative assistant know so that a longer time slot can be arranged. Most doctors slot 15 minutes per patient.
- ❖ Another way to be sure that everything is covered and noted at an appointment is to bring a trusted person for support, someone who will be able to ask questions that might be forgotten and also remember what the doctor said.
- ❖ Make sure it is clearly understood what role the family doctor and the oncologist play in the patient's medical care and find out how much communication there will be between them. Find out also what will be expected of the caregiver in regards to carrying information back and forth.
- ❖ Keep a journal that records everything that is said at an appointment. It will help because there is always so much to absorb. Some people ask their doctor if they can use a tape recorder.
- ❖ If the patient has a low neutrophil count or if his immune system is compromised in any way, ask if it is possible to wait outside the waiting room away from the general population or have the blood tests done where transplant patients' blood is drawn away from the general population.
- ❖ Be informed how to access community resources and the cancer care system and know exactly what is available for the patient and the caregiver and what their rights are. A hospital social worker should be able to help with this.
- ❖ Never assume anything. Always ask questions if you do not understand something. No question is silly.
- ❖ Always remember, the patient has a right to a second opinion. Asking the attending physician for this requires a diplomatic approach.



FINANCIAL TIPS

There are enough worries when a loved one is dealing with kidney cancer. The following are some financial tips that may help.

Check these out with a clear mind and while not in emergency mode:

- ❖ Check with the patient's health insurance to see what is covered regarding travel expenses for medical trips; coverage for both patient and caregiver; e.g., food, lodging, mileage/gas, etc. Keep all receipts in case.
- ❖ Check the patient's life insurance policy to see if there is a clause that waives premium payment totally or partially when an extended illness happens. This could mean quite a bit of savings if there is. There is usually a time limit, beginning with the date the official disability began.
- ❖ Check to see if the patient is eligible to claim medical and travel expenses on income tax and exactly what is allowable. Receipts will be required if eligible.
- ❖ Check to see if the patient is eligible to claim disability on income tax.
- ❖ When filling out short or long term disability forms, always make a copy to refer back to when completing subsequent evaluation forms.
- ❖ Make sure to get disability forms in by the due date as it could mean forfeiting the benefit if not.
- ❖ If long distance travel is involved to get to and from appointments or treatments, check with the hospital social worker to see if there is inexpensive lodging available to cancer patients and caregivers within a reasonable distance of the hospital. Check to see if the caregiver can stay there alone while the patient is hospitalized as well. If staying at a hotel, inquire if they have medical rates. These are sometimes cheaper than corporate rates. A Proof of Appointment Attended form obtained from the Administrative Assistant may be required.
- ❖ Check to see if the hotel has a free shuttle service to the hospital and back and what hours they run.
- ❖ **Warning:** Be careful of hospital long distance charges on room phones. Outgoing long distance calls are sometimes charged extra, local calls are usually not charged other than the initial fee. Use a cell phone only in cell

phone capable areas of the hospital or use public payphones with a phone card.

- ❖ Have a telephone and/or email chain set up so it is not necessary to call everyone with updates. Choose one or two contact people and give them a list of names and numbers to call or email. This will cut down on time, stress and cost.
- ❖ If the patient is in the hospital for an extended period of time, check to see if arrangements can be made for food trays that were originally ordered for patients who cannot eat at scheduled meal times or are being discharged be provided to the caregiver.
- ❖ If traveling outside the country check to make sure the travel insurance covers pre-existing conditions and exactly what the criteria is. Each company has different criteria and definitions. It is important to read the requirements and the fine print.
- ❖ If you do not already have a pharmacy that you use regularly, look for one that provides incentives for their customers such as points or coupons that can be redeemed as purchase dollars in the store. Pay with your credit card that gives extra points (paying the monthly total off) and get more benefit yet again.
- ❖ Have a pair of earphones available to bring to the hospital. It will save a few dollars when renting a television. Save these in case of another visit.
- ❖ Check with the cafeteria for coffee cards that offer a free coffee after several purchases have been made.
- ❖ Check with the Social Worker or the Oncology reception desk to see if there are any programmes that help cover parking costs.
- ❖ Try to get copies of reports and test results from the doctor's office rather than the hospital to avoid large costs.



CAREGIVER'S EMERGENCY BAG

Have a bag packed and in the hall closet ready to go at a moment's notice. Do not use the trunk of the car as temperature changes might be detrimental to the contents. If not a small suitcase then a large beach bag will do. It should hold much of what is needed to get through an emergency night or couple of days stay at the hospital with a patient. A close friend should also be shown where the bag is in case there is not enough time to retrieve it. (A bag for the patient might be kept in the same location.) **Do not bring anything of value to the hospital and never leave a purse or wallet unattended.**

Please remember that most hospitals are now scent-free. Be considerate of others and use unscented products, eg., deodorant, hair products, hand lotion, etc.

Pack:

- ❖ a toothbrush, toothpaste and dental floss as well as mouth wash
- ❖ unscented face soap and unscented hand lotion – face cloths and towels are available on the unit
- ❖ unscented deodorant
- ❖ clear eye drops to ease the caregiver's tired eyes
- ❖ a brush or comb
- ❖ an extra pair of underwear
- ❖ gum, lozenges (hospitals can sometimes be very dry)
- ❖ a warm sweater, even in summer as air conditioned rooms can be quite cool
- ❖ some snack or energy bars (don't let these get too old – change to fresh ones as indicated on the *Best Before* label)
- ❖ instant hot chocolate and oatmeal cereal packs are handy and usually can be made up with hot water at the coffee stand on the unit
- ❖ a couple of water bottles

- ❖ small change for vending machines when cafeteria is closed (loonies, toonies and quarters)
- ❖ a book to read, some magazines, knitting, etc.
- ❖ a D.V.D. player with DVDs, an iPod &/or an electronic photo frame for the patient
- ❖ family photos are nice for the patient to see, if bringing special photos make sure to bring copies, not the only originals (photocopies work well)
- ❖ notebook and pens to record information
- ❖ antibacterial hand wipes and kleenex
- ❖ the patient's updated list of medicines and dosage amounts, **don't forget to bring the patient's kidney cancer drugs. The hospital pharmacy will not have them in stock. When travelling from Emerge to the unit keep the patient's cancer drugs with the caregiver to avoid them being lost in the move.**
- ❖ 2 days supply of medication that the caregiver takes regularly
- ❖ an address book with important personal contact numbers or email addresses – establish a good time when people can phone the patient in the room.
- ❖ **Do not put your purse or bags on the hospital floor, place them on a chair or in the patient's locker.**



HOW TO HELP THE HOSPITALIZED PATIENT

- ❖ Every time the patient gets up to go to the bathroom, smooth out the bed sheets and plump and re-position the pillows.
- ❖ Every unit has a heating blanket closet, usually tall and stainless steel. Ask the nurse if you can get the blankets as needed for the patient instead of calling the nurse and using their valuable time. Be sure to replace the blankets from the storage rack to the unit so there will always be warm blankets. Put the replacements at the bottom of the pile to give them a chance to warm up so that the next person does not reach in and get a cold blanket. Make sure the closet door is securely closed to keep the heat in.
- ❖ Post surgery, extra pillows positioned appropriately around the patient will make the patient more comfortable. Discuss with the patient the best position for relief.
- ❖ Doggy bone pillows are great for the hospital. They support the patient's neck when he/she is too fatigued or weak. Place the pillow in a strong plastic bag, tape around the contours and use a pillowcase from the unit. Get fresh pillow cases from the storage rack.
- ❖ If the patient is experiencing extreme sweating, replace the bed sheets and pillow cases while the patient is up and in the washroom if possible. Waiting for staff could take awhile and the patient would have to get up again perhaps interrupting a nap.
- ❖ Sometimes a body pillow can help with post surgery back aches and pains. The patient can tell the caregiver where to position it for best relief.
- ❖ If the patient is having trouble eating hospital food during a prolonged stay and has no dietary restrictions, in some cases the dietician is able to order food from the cafeteria. It is better to have something in the patient than nothing.
- ❖ Antibacterial hand wipes are nice for the patient to have on the portable bed tray along with a box of tissues from home (the small tissues at the hospital just don't cut it) as well as a bottomless glass of fresh water. Always check to see if the patient is allowed water before giving it.



HOW FRIENDS CAN HELP

People do truly want to help in a time of difficulty but just don't know how and everyone's situation is different. What one person needs is not what another might need. Having a list of what people could do to help in an emergency would be very helpful. Make up this list when not in crisis mode and keep it handy so that should the time come, it is ready. Allow friends and relatives to choose what they can do to be helpful before an emergency. Let them be part of the healthcare team. The list below is just a sample and can be adjusted and added to according to the situation.

- ❖ Set up a telephone or email chain or blog now. Only one person needs to be contacted and he/she can convey patient updates to everyone that is on the list. With a blog people can send in postings and good wishes as well as get updates.
- ❖ Have someone keep a key to the house. Show this person the location of the emergency hospital bag ahead of time so they can bring it to the hospital if there was not enough time to grab it.
- ❖ Designate someone in advance to take care of the pets, either in their own home or the pet's home. Go over any medications that the pets need and where they are stored.
- ❖ Designate someone in advance to mow the lawn or shovel the walkway to the front and back door and arrange to keep the driveway blown out when needed.
- ❖ Designate someone to check the house daily, and water indoor and outdoor plants.
- ❖ Designate someone to have fresh fruit, milk and bread at the house.
- ❖ Designate someone to pick up the newspaper and mail each day or put a hold on the newspaper until further notice.
- ❖ Make sure the porch lights are not left on all day advertising that the owner is absent.
- ❖ Organize someone to take care of the garbage and recycling. Leave a list of the pick up dates.
- ❖ Organize lifts to and from the hospital if fatigue is an issue with the caregiver.

- ❖ If people would be more comfortable giving something, there is always a day's rent on the TV; a small basket of fruit that won't spoil too quickly – no nuts; newspapers or magazines or a good book; a takeout coffee or tea when they visit; a muffin from the cafeteria, etc.
- ❖ Accept respite care from friends during recuperation or hospice situations even if it is just to take a long relaxing bath. A caregiver needs to take care of oneself so he/she can effectively take care of the patient.
- ❖ Quite often the hospital is not permitted to give out the room number to someone outside the family. If a person would be a welcome visitor for the patient the room number will need to be known before the visit.



NOTES FROM ASCO (American Society of Clinical Oncologists) 2010

- ❖ Caregivers need information, facts and understanding across transitions, not just at diagnosis. Every time there is a change there is added stress, even if less care giving is required.
- ❖ Caregivers also need a clear set of expectations, as well as guidance, counselling, direction and skills to make decisions and solve problems.
- ❖ Caregivers may require new skills such as planning, financing, etc.
- ❖ Specific directions are needed in the form of having to supervise adverse effects, decision making and problem solving.
- ❖ Caregivers need to learn about pain and symptom monitoring, interpreting, as well as when and what actions to take.
- ❖ Coordinating care, acquiring medications, handling medical equipment, reporting urgent symptoms, providing direct care and custodial care all need to be addressed.
- ❖ Caregivers know a lot about burden, distress and depression but little about how to help family members provide cancer care.
- ❖ Family members are not prepared to be caregivers and to deal with cancer drugs. They need support.
- ❖ Caregivers are lost in the formal cancer care system and use few community resources even if available because they do not know how to access them.
- ❖ Professionals need to consider family members as partners.
- ❖ Caregivers are faced with a lack of information and uncertainty. They experience early and continued trial and error without guidance from the system. The system provides little for them.
- ❖ Caregivers should be considered a part of the patient care plan.
- ❖ Risk factors for caregivers are the condition of their own physical and mental health (they need emotional support for anxiety, uncertainty, depression and anger) and also the stresses of how to manage their multiple other roles (work, family, social, competing demands).

- ❖ It has been found that 12 months after treatment ends, family members are still under stress and still “on call”. They feel a loss of control of family and life. They can suffer insomnia, fatigue, depression, anorexia or other eating disorders.
- ❖ One point of interest concerning care giving was brought forth:
“Seeing a loved one in pain activates the same brain areas involved when one experiences pain oneself.” Singer & Lamm 2009 Imaging Studies of Empathy



RESOURCES

Books:

- ❖ *100 Questions and Answers about Caring for Family or Friends with Cancer*, second edition by Susannah L. Rose MS, MSSW & Richard T. Hara PhD, MSSW Jones and Bartlett Publishers, 2010
- ❖ *100 Questions and Answers about Kidney Cancer* by Steven C. Campbell MD, PhD, Brian I. Rini MD, Robert G. Uzzo MD, FACS, Brian R. Lane MD, PhD, Stephanie Chisholm PhD Jones & Bartlett Publishers, 2009
- ❖ *100 Questions and Answers about Life After Cancer: A Survivor's Guide* by Page Tolbert, LCSW & Penny Damaskos, LCSW, OCSW Jones and Bartlett Publishers, 2008
- ❖ *How Can I Help? Everyday Ways to Help Your Loved Ones Live with Cancer* by Monique Doyle Spencer, Adams Media 2008
- ❖ *What Can I Do to Help? 75 Practical Ideas for Family and Friends from Cancer's Frontline* by Deborah Hutton Short Books 2005
- ❖ *Incidental Finding Essays on Renal Cell Carcinoma* by Cynthia Chauhan Tall Grass Books, 2006
- ❖ *Living with Kidney Cancer Patient and Family Reference Handbook Pfizer 2009* The authors include professionals from various medical fields and a patient advocacy organization, Kidney Cancer Canada. The list of names can be found in the handbook and the books are available at most cancer care centres and doctors can request them from Pfizer.
- ❖ *When Someone You Love Has Cancer: Comfort and Encouragement for Caregivers and Loved Ones* Harvest House Publishers, 2009
- ❖ *I Don't Know What to Say: How to Help and Support Someone Who is Dying* Robert Buckman, Key Porters Books Limited, 2005
- ❖ *The Healing Circle Dr. Rob Rutledge, MD, Timothy Walker, PhD The Healing and Cancer Foundation 2010* Integrating science, wisdom and compassion in reclaiming wholeness on the cancer journey - The Healing and Cancer Foundation

Websites and videos:

- ❖ Cancer Care Connect: Care Giving for Your Loved One with Cancer presented by Diane Blum MSW <http://www.cancercare.org>
- ❖ Cancer Care Connect Education Workshops at www.cancercare.org/podcasts
- ❖ Caring for the Caregiver, National Cancer Institute <http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver>
- ❖ You Have a Right to Be Hopeful National Coalition for Cancer Survivorship <http://www.canceradvocacy.org/resources/publications/hopeful.pdf>
- ❖ Patient and Caregiver videos: www.kidneycancerCanada.ca /About Us
- ❖ Patient Stories www.kidneycancerCanada.ca /About Us
- ❖ Canadian Urological Association Kidney Cancer Treatment Guidelines www.kidneycancerCanada.ca /Resources/Kidney Cancer Treatment Guidelines

