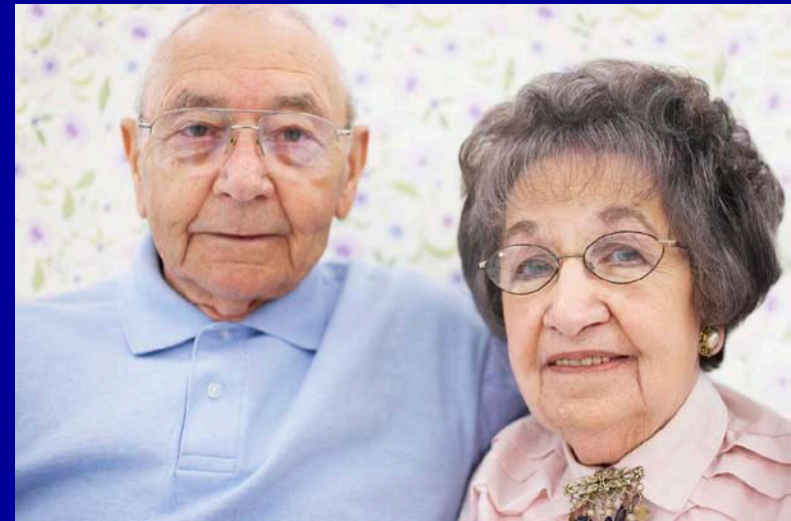
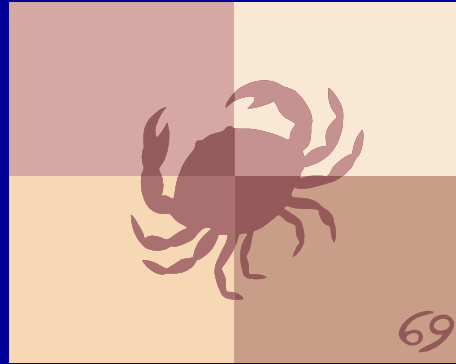




# HOW CAN WE HELP? WISDOM FROM CANCER PATIENTS

**Nancy Payeur, MSW, RSW  
Patient & Family Counselling Services  
Vancouver Island Centre**





Discovery...Diagnosis...

*As soon as you hear that word  
“cancer” – your world changes.*





# Worried Waiting... Medical Workup

*Everything is unreal...you go to all these appointments...and you wait for what seems like forever to know what the results are and what they mean.*

*You truly are “living in the in-between”...the waiting is the worst.*



# The Love & The Pain – Families & Friends

*If it could only be me that has the cancer...  
I feel so helpless...what can I do really?  
I'm afraid to let her see how scared I am.*

*I don't bring that up –  
I don't want him to know  
I'm even thinking that way.*

*Really can't show my worries –  
feel I must stay positive  
for her.*





# Challenges for Patients – At The Beginning...

- Existential Crisis – “Why Me”?
- Self Definition – Healthy to Cancer Patient
- Looking Death in the Face
- Complex Medical Information & Systems
- Treatment Decisions
- Telling Family & Friends

# The Love & the Pain – for Patients

*I can't leave my kids without a mother...  
I'm not ready to die.*

*Why me? I've lived a healthy life!*

*We didn't plan on this happening to us...*

*I have to be strong for everyone else.*

# The Love & The Pain...

*Everyone keeps telling me to BE POSITIVE...if I hear that one more time...\$\$%%###!*

*People say “but you look so good” it’s like they don’t believe I really have cancer.*

*Telling friends and family was the worst.  
I ended up having to deal with their reactions and taking care of them.*



# Treatment Decision-Making & Treatment Process

*I keep looking on the Internet and I feel overwhelmed. My wife won't let me go on without her sitting with me any more.*

*My doctor says I have to choose – but what do I know about cancer treatment? I wish she would just tell me what to do!*



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*I have become a magnet for layman medical advice, assessors of attitude and all knowers' of God's intentions. If I just switch to this diet, or take that supplement, if I just smile and have a great attitude or if I believe in God enough, I will be healed. I shouldn't complain, because I'm lucky to be alive. Heck, anyone could be hit by a bus tomorrow. Everyone is a cancer critic.*

# Challenges for Families – During Treatment

*My wife takes care of so much...I am struggling to work and deal with everything myself now.*

*Now he is leaning on me – it is so hard to see him this way.*

*Cancer is taking over our lives. I miss our old life already. Feels like a parallel universe.*

*The drop in income – very tight for us now.*

*Chemo is hard...I cried when my hair fell out.*

*Some are so kind - others have disappeared.*



## After Active Treatment

*I'm guess I'm supposed to feel  
happy that treatment is over...but  
I'm just confused about what life  
holds for me now.*

*I worry about recurrence.*



# After Treatment

*Everyone seems to think that it's over...but for me...it's not over. I've been changed by this experience.*

*I just want to forget about it and move on...but that's hard to do when you are still dealing with the side effects and you're not able to do what you could easily manage before.*

*Life seems more precious...and I am making some changes in my priorities.*

*I got so much support from family and friends and the medical team during treatment...but now everyone has gone back to their normal routines and have sort of forgotten about me.*

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*I am a cancer patient and I am alive but I don't consider myself a survivor. I do not identify myself as a warrior. I am not fighting any battle. I am not a martyr, an athlete, a cheerleader or a sugar coated Pollyanna, nor do I have the answers to the universe because of my cancer diagnosis. My attitude isn't open for public assessment. I don't have pink runners and if I ever say my cancer was a gift, you'll know to lower my medications.*



# Approaching End of Life

*Some of those close to me don't seem to know how to deal with this...I'm not dead yet and I wish they'd stop treating me as if I were.*

*It's BOTH/AND – we are living life day to day and we have some good days which gives us hope...AND I am getting my affairs in order knowing what's coming.*

**How To Help:  
Top Tips from Patients  
& Family Members**

# TIP #1: It's not about you...

*It's about **THEM**.*



- Their comfort.
- Their support.
- Their needs.
- Their preferences.
- Their feelings.

# Tip #2 – Ask Permission

*Would this be helpful?*

*Would you like me to...?*

*Are you okay with this?*

*Which would you  
prefer?*

*What works for you?*



# Tip #3 – Listen with your heart.

- Talk less; listen more.  
Listen with your eyes too.
- Pay attention to what they are saying.  
(And not saying).
- Follow their lead.
- Give them choice over anything you can  
(You may want to talk about this or not –  
I'm here for you no matter what).

# Tip #4 – Give them a break... From “Cancer Land”.

- Funny movies
  - Good books
  - News from the world “beyond”
  - Gossip and tid-bits
  - Work news
  - Some anecdotes from your life
- (NOTE: Non cancer related!)**

# Tip #5 – Avoid advice giving on health matters!

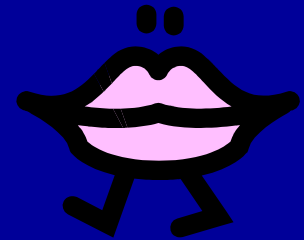
*Sending articles, emails, web sites, books and/or giving advice related to someone's cancer treatment or health matters...is generally not helpful or appreciated!*

Raises anxiety

Indicates lack of trust

Decreases self-confidence and hope

**#6 – Put brain in gear before...  
opening mouth**



**Stories about cancer patients who died =  
not helpful!**

**Face your own issues about serious illness  
and/or death.**

# # 7 When you make a mistake – apologize!

- From the heart
- Briefly
- Reconnect
- Move forward



# TIP #8 – Be PROACTIVE

## (Anticipate needs & follow through)

- Once more with feeling:  
It's ABOUT *THEM!*
- Think about who they are, their lives and current challenges.
- DON'T SAY “call me if I can do anything”.
- Coordinate rides, child care, meals, treats.
- Think about practical daily needs too.

# Tip #9 – It can be little things

- Weekly card
- Messages “my thoughts are with you”
- Prayers
- Foot creams and back rubs
- A small treat.
- Child (or Spousal!) Care



# Tip #10 – It can be big things

- Tell them they matter
- Share memories
- Touch & Comfort
- Joy & Humour
- Time with them
- Acceptance & Sensitivity
- Staying connected





## Question for Reflection –

*What is one thing YOU have learned about dealing with cancer? (As a patient, family member or friend)*

# What Helps Families Cope

- Supportive Relationships
- Honest + Direct Communication
- Acceptance of Differences
- Role Flexibility (“Men with Murses”)
- \$\$\$ - Financial Resources
- Older Age! (=Wisdom?)
- Spirituality – Connection to Meaning
- Active Problem Solving Approach
- “Benefit Finding” Frame



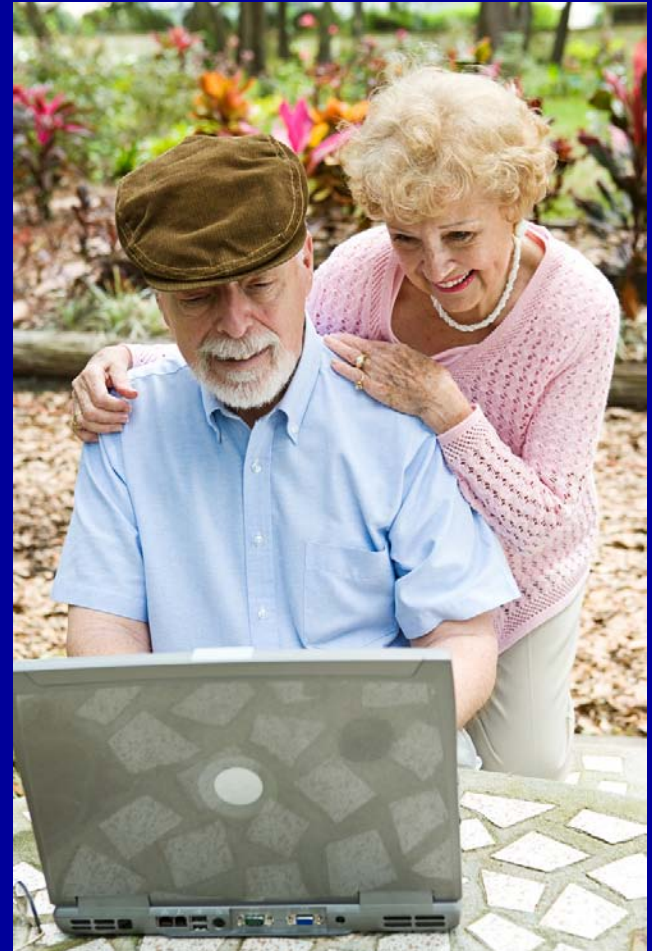
# Top Ten Tips – For PATIENTS

1. Live NOW. Carpe Diem.
2. Accept Offers of Help.
3. Acknowledge Your Feelings.
4. Creative Expression: Write, Paint, Blog, Jog...
5. Ignore Unwanted Advice & Avoid Obnoxious People.
6. Focus on What You Can Control – Let Go of the Rest.
7. Take Breaks from “*Cancer World*”.
8. Avoid Beating Yourself Up
9. Find the Humour & Hope
10. Make Time for “The Big Rocks”



# Top Ten Tips from/for FAMILIES

1. Don't go solo.
2. Match people's skills to tasks at hand.
3. Learn about resources.
4. Ask questions.
5. Put technology to work.
6. Seek *credible* information.
7. Take time out.
8. Self-care & Pacing.
9. Delegate the mundane.
10. Accept your own limits.



# Top 10 Tips for Helping Kids

1. Language & info geared to their needs (Secrets don't work).
2. Recognize and normalize feelings.
3. Anticipate their worries.
4. Provide “time outs” from cancer.
5. Listen!



# Top Ten Tips for Helping Kids

6. Physical Affection
7. “Okay to be a kid and have fun”
8. Resources – books, people, DVD’s
9. One on one time.
10. Get Input and Give Choices When Possible.



# Resources

- [www.bccancer.bc.ca](http://www.bccancer.bc.ca) - *Coping with Cancer* section – links and recommendations.
  - [www.cancerinmyfamily.ca](http://www.cancerinmyfamily.ca) – for Children and Parents
  - [www.cancerchat.ca](http://www.cancerchat.ca) – Online Groups
  - BCCA Libraries – Vancouver, Victoria, Kelowna, Fraser Valley, Abbotsford.
- \*\* *Resource Lists – Pick one up TODAY!\*\****

# Patient & Family Counselling Services

- Individual, Family & Group Sessions
- Counselling, Support & Referrals
- On-line, Telephonic & In-Person Services
- Public & Professional Education
- Up to 18 months post treatment
- For patients, family
- No Charge



# Discussion

**Does any of this information fit for  
you and your family or friends?  
Comments?**

