

# WHEN A LOVED ONE HAS CANCER

What to say and what to do as a supporter

## WELCOME EVERYONE!

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# OVERVIEW OF TALK

- Practical suggestions plus
- Advice about emotions and relationship issues
  - Diagnosis
  - During treatment
  - After and between treatment
- Taking care of you

# DIAGNOSIS!!



Ruth Fields

# WHY LEARN ABOUT CANCER AND THE MEDICAL SYSTEM?

- Understanding helps you feel in control
- You will be better able to deal with problems
- Helps you make better decisions
- Your loved one will get better care

# HOW TO GET THE MOST FROM THE MEDICAL SYSTEM

- Try to understand what's happening
- Prepare for each visit to your cancer specialist or family doctor
- Contact your doctor/nurse if you have questions or concerns
- Ask for extra care if you need it

# IF YOU WANT MORE INFORMATION

- Your cancer doctor is the best person to individualize the information and give you medical advice

# SOURCES OF GENERAL INFORMATION ABOUT CANCER AND ITS TREATMENT

- To talk to a person:
- Patient navigators
  - On mainland Nova Scotia
  - 1-866-524-1234
- Librarian at the Hospital

# Cancer Information Service

1 888 939 3333

- Service of Canadian Cancer Society, a community-based organization
- Free, 9am-6pm helpline to an information specialist draws on world-class database
  - Provides information not medical advice
  - Advice for emotional issues, communication etc
- Available in four languages
- They will email/mail you complete info package as summary of conversation
- List of all resources nationally and locally
  - Volunteer drivers, wig bank, accommodation...

# WEBSITES PROVIDING GENERAL INFORMATION ABOUT CANCER

- Cancer Care Nova Scotia's Website
  - [www.cancercare.ns.ca](http://www.cancercare.ns.ca)
  - Look under patients and families links and "information for patients and families"
- Canadian Cancer Society: [www.cancer.ca](http://www.cancer.ca)
- National Cancer Institute (USA) provides easy-to-understand summaries at
  - [www.nci.nih.gov/cancertopics/pdq](http://www.nci.nih.gov/cancertopics/pdq)

# **GETTING THE MOST FROM YOUR DOCTOR'S VISIT TAKES PREPARATION**

- **Before, during and after the visit**

# HOW TO GET MOST FROM A DOCTOR'S VISIT

## Before the visit

- Create a concise summary of symptoms
- Bring a list of current medications and allergies
- Write down your questions before the visit
- Someone should accompany loved one
  - Decide who will make record of the visit
- +/- Create a file with all the test results
  - You can get a copy by visiting medical records

# HOW TO GET THE MOST WHILE AT THE VISIT WITH THE DOCTOR

- Be honest and open
- Speak up if you're feeling overwhelmed:  
"I'm not sure I understand"
- Wait till the summary then ask your most important questions first
- Take notes or record the interview
- Find out what to expect eg. side effects and who you should call in case of problems
- Nurses are invaluable - eg. with care plans

# HOW TO GET MOST FROM YOUR DOCTOR – AFTER THE VISIT

- Keep a journal and list of results
- Know what to do if side effects occur
- **KNOW WHO TO CALL!!**
- Ask for family conference

# PROBLEMS WITH DOCTOR

- You, a different family member or friend may be able to do the talking
- Call to clarify information or ask for appointment
- Ask for a second opinion if need be

# GETTING MORE PHYSICAL CARE

- Multiple services are available
  - Home care nursing
  - Palliative Care Team
  - Other services in the health care system
  - Social Work can help coordinate
- **ASK YOUR NURSE OR DOCTOR!**

# DIAGNOSIS



Cathrine Burris, Tranfigured

# UNDERSTANDING THE EMOTIONAL ROLLERCOASTER AT DIAGNOSIS

- It's normal for you or your loved one to feel any and every emotion including:
  - Shock
  - Worry, anxiety, fear
  - Guilt
  - Loneliness
  - Sadness
  - Hopelessness
  - Anger
- These emotions can be exaggerated or come out unexpectedly

# WHAT DO YOU DO WHEN YOUR LOVED ONE IS BREAKING DOWN

- Listen
- Acknowledge
- Stay with the uncomfortable feelings
- Only after this, reassure in ways you can truly deliver
- "I'm going to be with you through all of this"

# BLOCKS TO STAYING PRESENT WITH DIFFICULT EMOTIONS

- We're uncomfortable with these feelings in our loved one
- We think if our loved one breaks down they will never be happy again
- We think our job is to keep things "positive" all the time
- We're scared of the future

# WHAT DO YOU DO WHEN YOU ARE BREAKING DOWN

- Express your emotions
- If you can, tell your loved one
- If not, talk to someone else

**Emotional distress is expected  
but ..if you or your loved one are:**

- feeling very low, blue or hopeless
- unable to enjoy life
- having difficulty making decisions or returning to “normal” life
- Experiencing excessive worry or anxiety
- Not able to talk about cancer without becoming extremely upset
- There is help available

# HOW TO GET HELP WITH EMOTIONAL DISTRESS

- Tell your cancer doctor or nurse during the next appointment
- Schedule a visit to your family doctor
- Learn about the resources available to help (support groups, the Canadian Cancer Society, Cancer Program staff)

# AFTER DIAGNOSIS/ THE TREATMENT PHASE

- Keep getting the best conventional care
- Augment with healthy health habits
  - Diet, physical activity, relaxation, support groups
- Complementary therapies
- Use what worked in past
  - Eg. faith community

# THE ROLE OF NUTRITION

- Effective way to improve your health
- Should not be a source of conflict with your loved one
- Individualize to what works for your loved one
- Ask your doctor and professional dietician if persistent problem with
  - Ongoing unintentional weight loss or loss of muscle mass
  - Nausea and vomiting
  - Diarrhea / constipation
  - Treatment affecting the GI tract

# GENERAL NUTRITION ADVICE

- Choose a variety of food from all food groups daily
- 5-10 servings fruits and vegetables /day
- Choose lower fat food groups
  - Fat to make up < 20% of caloric intake
- Choose high fiber foods
  - Whole grain breads and cereals
- Drink plenty of healthful fluids
- Maintain healthy weight

# HOW TO GET MORE INFORMATION ABOUT NUTRITION

- Contact the professional dietician at the cancer centre
- American institute for cancer research : [www.aicr.org](http://www.aicr.org)

# EXERCISE IS SO BENEFICIAL!

- Effective way to improve energy, sleep, mood and overall health
- Loved one needs to listen to their body to guide themselves
- Individualize to phase of journey
  - Slowly increase the activity each week
- After recovery aim for at least 30min on 5 or more days a week

# FIND A WAY TO EXERCISE



# OTHER HEALTHY HABITS

- Maintaining a reasonable weight
- Get a good night's sleep - in the dark

# FIND A WAY TO RELAX



# SUPPORT GROUPS

- Gathering of people with a similar issue, usually for 2-4 hours a month
- Can help you with
  - Getting information
  - Learn ways to cope
  - Practical tips and support
  - A safe place to express your emotions
- Improve quality of life!
- Cancer Care Nova Scotia  
[www.cancercare.ns.ca](http://www.cancercare.ns.ca)
- Canadian Cancer Society

# END OF TREATMENT DISCONNECT

- End of treatment can be very stressful
- There are definite gender differences in how we cope with cancer.
- This may be more difficult for women than for men

# The We, You and I of relationships . . .



**Maintaining a sense of “we”  
as well as  
“I” (family member)  
and  
“you” (person with diagnosis)**

# Relationship “skews”:

- The illness comes to dominate every aspect of life – there is no room for “we”
- There is no room for “I” alongside “you” (the patient – caregiver skew)

## Myths that diminish the “we” . . .

- There is only one story about the experience of cancer.
- Sharing emotions and scary thoughts will burden (frighten, anger, overwhelm) my partner.
- He (she) ought to know what to say/do

# Jackie and Kevin

## Myths that diminish the “we” . . .

- A good partner gives up everything to care for their ill loved one.
- Care only goes one way – from partner to your ill loved one.

# Nourishing the “we” . . .

- Cancer is like an unruly child .  
. . . it needs structure,  
discipline and boundaries. . .

## Nourishing the “we” . . .

- Talk, talk, and talk some more.
- There is more than one “illness story” and
- there is nothing you can say that your partner hasn’t thought.

**Chantal**

# Nourishing the “we” . . .

- Remember what you always did to maintain connection with each other.

# ADVICE FOR THE SUPPORT PERSON (nurturing the 'I')

- Use what works for you
- Remember what's most important

# MAKE TIME FOR YOURSELF

- Rely on friends and family to help you
  - Transportation needs
  - Help with children
  - Ready-to-eat meals
- For those caring for a long time:
- Say 'NO' to non-essential activity

# WHAT TO DO - BODY

- LISTEN to your body
- Eat a balanced healthy diet
- Maintain a reasonable weight
- Exercise at least 3 times for 30 min every week
- Sleep - 7-8 hours/night
- See your Family Doctor
- Cherish your body

# WHAT TO DO - MIND

- Schedule a FUN and energizing activity every week
  - With and without your loved one
  - Do what you love
- Practise a relaxation technique
- Tell someone how you're feeling
  - See a therapist
- Find a balance and set your boundaries
- Have compassion for yourself

# WHAT TO DO - SPIRIT

- Nourish your spiritual life in your own way
- Listen to your inner wisdom
- Express your natural compassion

# ACKNOWLEDGEMENTS

**Thank you everyone!**  
**Lecture available at**  
**[www.robrutledge.ca](http://www.robrutledge.ca)**



# INTRODUCTION

- It's a real honour - just being here
- You can help
- It can be stressful to be a support person
- Use what works for you and your loved one
- Listening and trying to understand are key
- Make sure you and your loved one are paddling in the same direction
- The conditions will keep changing
- Take care of yourself

# CANADIAN CANCER SOCIETY

## “CANCER CONNECTION”

1 888 939 3333

- Matches loved one with a cancer survivor volunteer with similar diagnosis / situation
  - National database to find best match
- Telephone contact and/or face-to-face meeting
- Volunteer cancer patient listens and shares own experience

# DIET WILL VARY ACCORDING TO PHASE OF TREATMENT

- During cancer treatment and recovery
  - Maintain caloric intake – for energy / muscles
  - Use balanced diet if possible
  - Antioxidants from diet only
  - Chemotherapies : ask team about 'food safety'
- Living after recovery from treatment
  - Balanced diet with antioxidants from foods
  - If take oral supplements: never take more than recommended daily allowances
- Living with advanced cancer: individualize diet as per the treatment phase