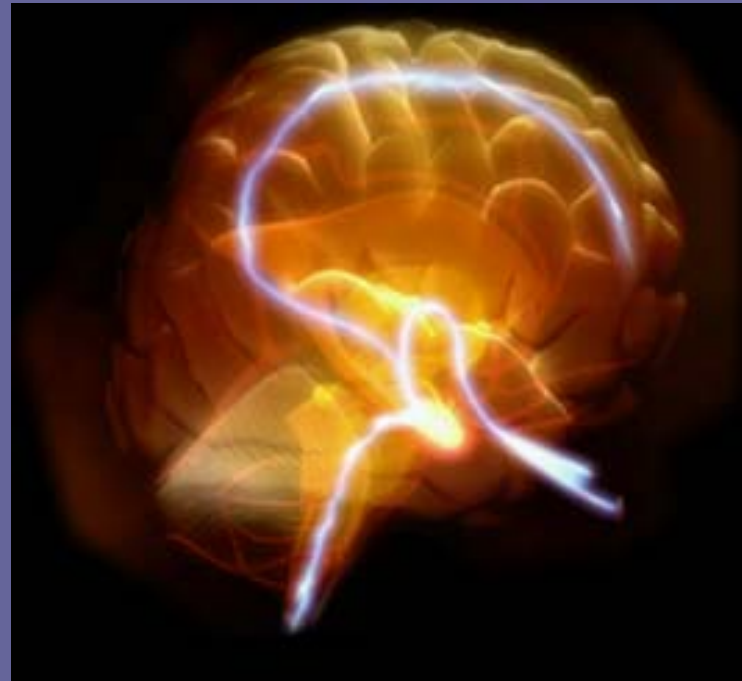


The problems
and Triumphs of
Caring for a
Loved One Who
has a Brain
Tumor



Living Well Through Cancer and Beyond

Being a Caregiver

Caring for someone who is ill can be very demanding, but in some ways it can also be very rewarding



This presentation focuses on caring for the loved one and for the caregiver during an illness

Resources for brain tumor patients and their families

- **Brain Tumor Foundation of Canada**
www.braintumour.ca
- **American Brain Tumor Association**
www.abta.org

In Calgary

- **Brain Tumor Support Group**
3rd Wednesday of every month, from 6:30 – 8:30 PM
Wellspring Calgary
#4 Parkdale Cresc. NW
Or Phone: 1-800-265-5106
- **Psychosocial Resources**
Alberta Cancer Board – Holy Cross site
2202 – 2nd st. SW Calgary
Phone: 403-355-3207



Resources for brain tumor patients and their families

Resources in Calgary (contn'd)

- **Family Caregiver Centre**
1509 Centre St. South
Phone: 403-303-6027
- **Hospice Calgary**
Suite 900
833 - 4 Avenue SW Calgary
Phone: (403) 263-4525
E-Mail: info@hospicecalgary.com

OFFICE HOURS:

Monday-Thursday: 8:30 A.M. - 5:00 P.M.
Friday: 8:30 A.M. - 4:30 P.M.

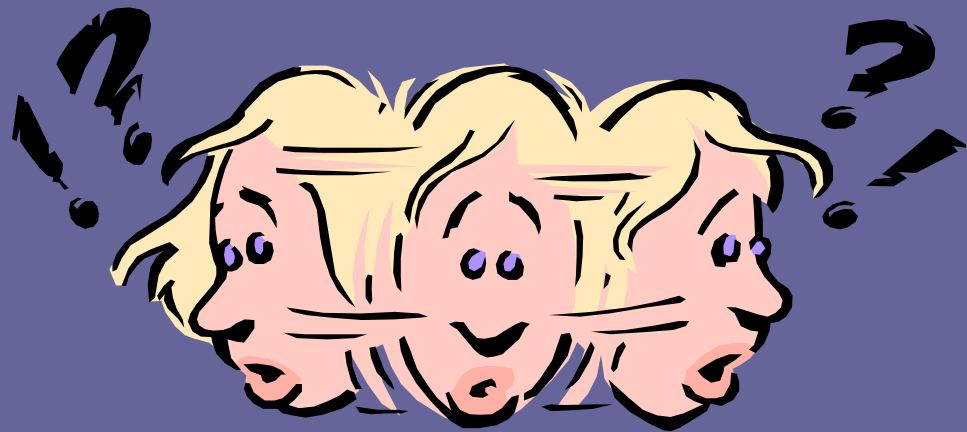


What to do at diagnosis time

Try to understand what has happened to your loved one

Educate yourself about the disease and the symptoms.

Ask questions about your loved one's disease, your treatment, your recovery.



A diagnosis of brain tumor produces a lot of uncertainty and anxiety. Prepare as best you can.

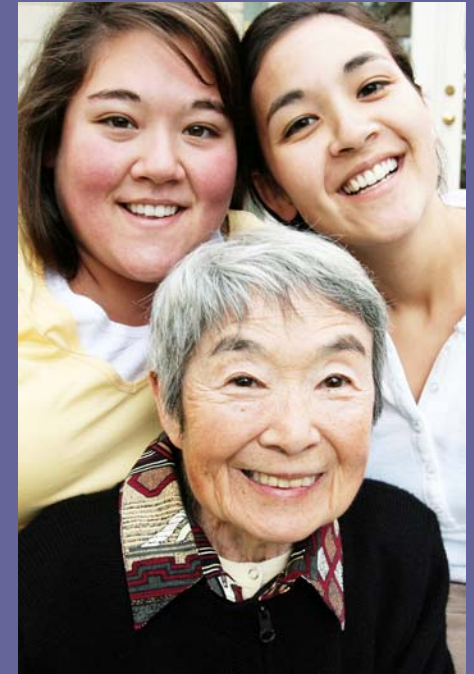
What to do at diagnosis time

Build up your personal support system



Tell your friends

Tell your family



Let them know what you need

Set times for phone calls, e-mails, etc. to avoid feeling overwhelmed. If needed, create a communication network



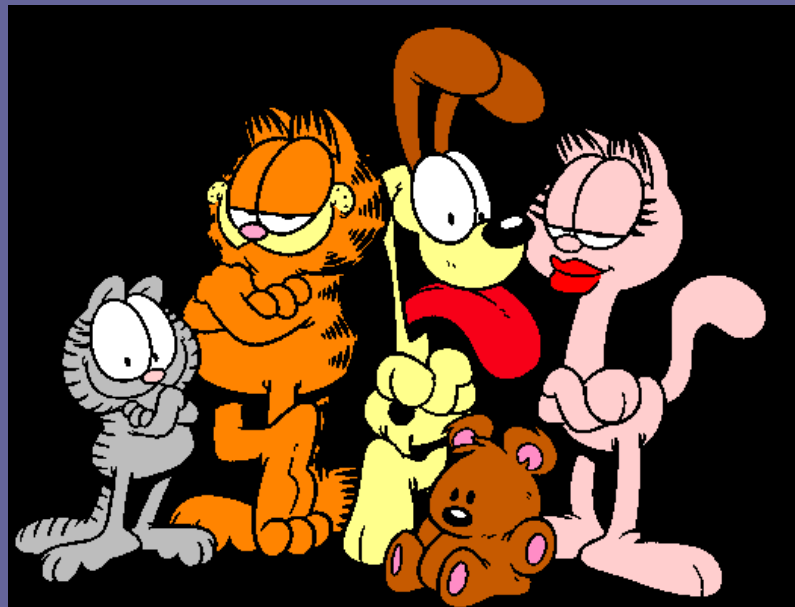
What to do at diagnosis time

Build up your community support system

Join a cancer support group

Keep in touch with your community organizations

Join online/internet support groups



Talk to your employer, colleagues, associates

Use professional resources (MDs, Nurses, Psychologists, Social Workers)

Keep in touch with your church, if that is part of your life

What to do at diagnosis time

Talk to your children

Let them know what is happening in simpler words

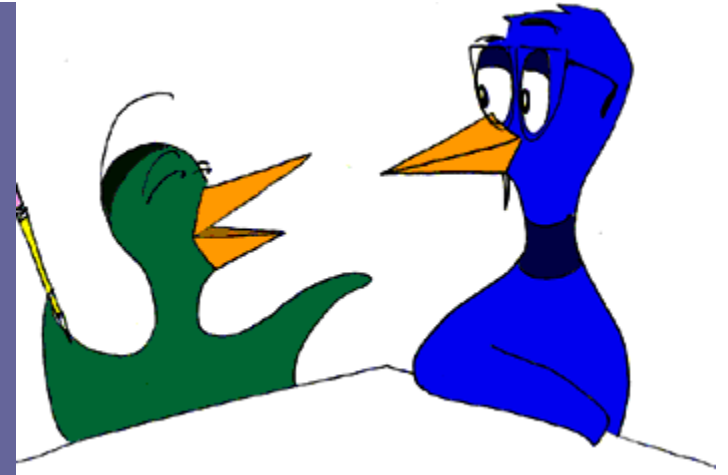
Do use the words 'cancer' and 'tumor' where appropriate

Reassure them that you will help your loved one take charge of the disease and the treatments.



Talk separately to children in different age ranges

Expect the conversations to be emotional at times



Maintaining Hope



Cultivate cautious optimism



Try to be realistic in your hope and expectations

A positive outlook usually helps maintain a better quality of life

Avoid “the prison of positive thinking”. It is okay to be sad, scared, or angry at times



Psychosocial Problems

1. Significant **reduction in quality of life** especially during treatments
2. About 35% - 40% of brain tumor patients report problems with **anxiety and/or depression**
3. **Depression** is strongly related to lower quality of life
4. **Fatigue** is a huge problem for this group during and often after treatment
5. **Relationship problems** can happen
6. About 26% of spousal caregivers of malignant brain tumor patients report emotional problems
7. Spousal caregivers of brain tumor patients report a lower quality of life than caregivers of patients in palliative care settings



Symptoms of Anxiety

Physical symptoms:

- abdominal discomfort
- diarrhea
- dry mouth
- rapid heartbeat or palpitations
- tightness or pain in chest
- shortness of breath
- dizziness
- frequent urination
- difficulty swallowing
- shaking

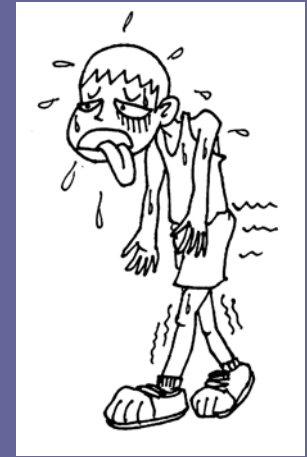
Psychological symptoms:

- insomnia
- feeling worried or uneasy all the time
- feeling tired
- being irritable or quick to anger
- an inability to concentrate
- a fear that you are going "mad"
- feeling unreal and not in control of your actions (depersonalisation), or detached from your surroundings (derealisation)





Symptoms of Depression



Physical symptoms:

- You feel exhausted a lot of the time with no energy . It is as if even the smallest tasks are impossible
- You have no appetite and you loose weight, even though you did not plan it. Sometimes, you eat too much
- You loose your sex drive
- You have difficulty sleeping or wake up very early in the morning and can't sleep again
- You may have physical aches and pains which appear to have no physical cause, such as back pain or abdominal pain



Symptoms of Depression

Emotional Symptoms:

- miserable and sad
- seldom enjoy previous pleasures
- social activity may feel hard or impossible.
- difficulty thinking clearly, concentrating, solving problems.
- feel like a failure and/or guilty much of the time.
- feel like a burden
- sometimes think life isn't worth living or have suicidal thoughts
- loss of hope
- irritable or angry more than usual.
- lack of confidence.



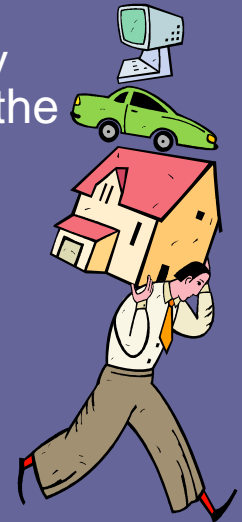
Problems associated with providing care

Roles change for spouses and caregivers, as well...



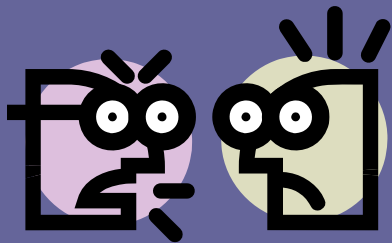
Well spouses may find that some of their needs may not be met in the same way that they used to be

Well spouses may shoulder more of the family burden



Well spouses may find themselves stressed out,

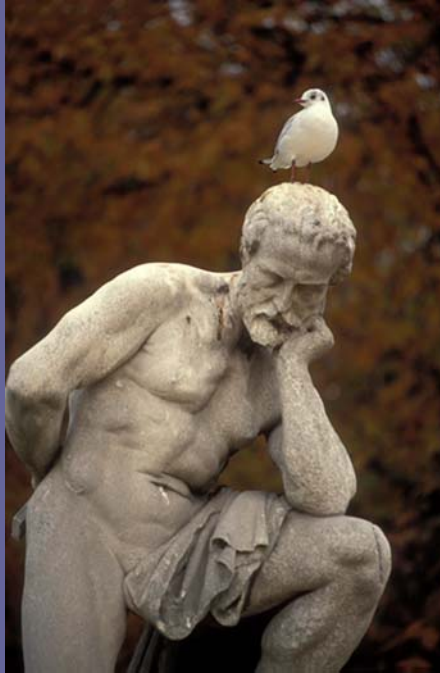
frustrated, angry, guilty, depressed, scared, overwhelmed, uncertain about the future. This is to be expected and these feelings need attention...



Signs of Caregiver Burnout

**Withdrawal
from family
and friends**

**Anger displayed
toward the patient
and others who
can't seem to help
or bring about a
cure**

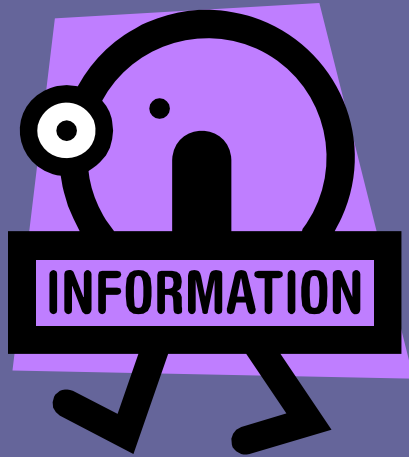


**Symptoms of depression
and exhaustion**

Health problems

**Caregiver may have a “positive
attitude” and publicly deny the
severity of the outcome of the
disease, yet he/she expresses fears
about the future**

Prevention and Help



Information about your loved one's condition leads to **realistic insight** about what you can and cannot do as a caregiver

Flexibility is a big advantage. You may need to do things differently, recognize what you can no longer do, and gain satisfaction from what you can do.



Prevention and Help for Caregivers

Look after yourself. Exercise, eat well, socialize, learn, do some fun things. Identify people who can help you in the short term for day-to-day tasks and in the long term

Inform yourself about your loved one's disease and treatments, and identify the professional sources of help. Try to understand the division of labor in the health care system and learn to identify who can help you at each stage of the disease



Stay away from potentially damaging behaviors:

monitor your use of alcohol, and try to avoid excessive shopping, gambling, and use of drugs



Prevention and Help

Don't try to cope all by yourself! If you get into some kind of trouble, **ask for help**. Things can take a lot longer and become a lot more difficult when you do them all on your own



Learn to count on other people's feedback to get a sense of whether you are in trouble. If people you trust keep telling you that things don't look good, do something about it.

Look at the positive side of care giving. Many caregivers look at the opportunity to provide care as a gift. They talk about feeling "blessed", "honoured", "privileged" to provide care to a loved one.

Could that be you, too?

