**Family Caregivers in Cancer Dr. Gary Mumaugh – Bethel University**

**Overview**

* Every year 1.6 million new cancer cases are newly diagnosed in the USA.
* Most patients will require some care at home from a family member or friend.
* Actually family caregivers form the foundation of current cancer care trends.

**Who is a Caregiver?**

* They are also referred to as informal caregivers.
* Family caregivers may be spouses, partners, children, relatives or friends who help with the patient with daily activities and home health care needs.
* Generally speaking, more women than men become caregivers.
* Most caregivers are related to the patient and most caregivers are over 55.
* Many cancer patients receive care at home. Hospital stays are much shorter and most treatments are given as an outpatient, not requiring a hospital stay.
* Cancer patients are living longer and want to be cared for at home as much as possible.
* This care is often delegated to family caregivers.
* These caregivers can be anyone who steps up to help out the patient.
* These family caregivers work with the health care team and have a huge impact on the quality of life of the patients.

**Caregiver’s Tasks**

* Caregiver’s are no doing a lot of what use to be performed by health care providers in hospital and clinic settings.
* Tasks are varied but could include helping with medicine, doctors’ visits, schedules, and navigating health insurance concerns.
* Care could also include emotional and spiritual support and helping the patient make decisions.

**It is important that the caregiver be a part of the health care team from the start.**

* The family caregiver has a very important job of watching for changes in the patient’s medical condition while also giving long term care.
* Family caregivers can help plan treatment decisions, make decisions, and carry out treatment plans all through the different phases of treatment.

**The Caregiver’s Point of View**

* Caregivers need help and emotional support.
* Every caregiver responds in his or her own way to the diagnosis and prognosis.
* The caregiver’s need for information, help and support is different than what the patient’s need.
* The caregiver’s role changes as the patient’s needs change during and after cancer treatment.

**At Diagnosis**

* Family caregiver’s take an active role that begins when the cancer is diagnosed.
* The caregiver has to learn about the cancer being diagnosed.
* The caregiver has to learn new medical terms.
* The caregiver also goes with the patient to new places for treatment and helps the patient with treatment decisions.

**During Treatment at the Hospital**

* The patient may ask the caregiver to be the one to talk to the health care team and make important decisions.
* The relationship between the caregiver and the patient affects how well this works.
	+ Disagreements and arguments between the patient and the caregiver can have an effect on treatment choices.
* During the active treatment phase, a caregiver needs to meet the demands of supporting the patient as well as the demands of home, work and family.

**During Care in the Home**

* ****The move to the home care setting is pretty stressful.
* The patient would rather be at home in a familiar and comforting place.
* The return home usually means more work for the caregiver.
* The caregiver may also be asked to
	+ Take on the patient’s household duties.
	+ Be a companion to the patient.
	+ Take care of medicines and meals.
	+ Schedule hospital visits and arrange for transportation.
	+ Work through the health care system for the patient.
	+ Arrange for home visits of therapists, nurses and other professionals.
	+ Handle insurance matters.
	+ Deal with medical emergencies.

**The Caregiver’s Point of View - Continued**

* Caregivers worry about how they will be able to do all these tasks and take care of themselves.
* Often, the caregiver gives up social activities and misses work.
* This can be challenging and emotionally and financially draining.

**After the Treatment Ends**

* Some patients and caregivers expect that life will go back to the way it was before the cancer was diagnosed.
* Caregiver stress continues after treatment stops because now roles have changes again.
* Some caregivers have problems adjusting for 1-2 years.
	+ This is partly due to the worry that the cancer will return.
* When the caregiver is the spouse, there can be sexual challenges.
* Studies have found that these adjustments are usually handled in time.
* Obvious problems may occur if any of the following are present:
	+ Relationship issues with the patient and caregiver.
	+ Poor communication between the caregiver and the patient.
	+ Lack of social support

**At the End of Life**

* This brings a new set of challenges for the caregiver as they grieve and adjust to the “new normal”.
* At the end of life, the patient depends even more on the caregiver for physical, emotional and spiritual support.
* The patient’s symptoms may be more difficult to manage.
* The caregiver is often overwhelmed with these new challenges.
* The caregiver may feel even more stress when the patient goes into hospice care.
* Numerous studies have demonstrated that caregivers quality of life and general health are much worse when giving the patient active end-of-life treatment.
* End-of-life support services will include the following:
	+ A team approach helping the patient and family with their physical, emotional, social, spiritual, and economic needs in order to improve the quality of life of the patient.
	+ Caregiver’s medical decisions and managing the patient’s symptoms.
	+ Watching the caregiver for signs of distress and burnout and work with them to get them the help they may need such as respite care.

**Roles for the Family Caregiver**

* The family caregiver has many roles besides giving the patient hands-on care.
* The caregiver takes on different roles so that the patient gets all the information, support, and treatment that they need.
* The major roles are
	+ Decision maker
	+ Advocate
	+ Communicator

**The Caregiver as a Decision Maker**

* Doctors, caregivers, and patients are partners in making decisions.
* Making a decision involves getting the information and understanding it.
* In order to make treatment decisions, caregivers will become researchers.

**The Caregiver as an Advocate**

* The family caregiver knows and understands the needs of the patient.
* The caregiver advocates for the patient by providing information and feedback to the health care team.
	+ ****This information can be helpful to the medical team to in deciding and analyzing treatment options.
* As the patient’s advocate, the family caregiver may:
	+ Talk with the health care team about the patient’s needs and wishes.
	+ Research information.
	+ Find doctors and specialists.
	+ Monitor the patient for any changes.
	+ Help the patient with any treatment.
	+ Update the health care team of any new symptoms or changes.
	+ Pay the patient’s bills and process insurance claims.

**The Caregiver as a Communicator**

* Good communication between the patient, doctor, and caregiver can dramatically improve the patient’s care.
* The family caregiver will often take on the role of speaking for the patient while also keeping the patient informed.

**Roles for the Family Caregiver - continued**

* Doctors need to hear about the patient’s concerns, and caregivers need to understand the disease and treatment options.
* Poor confusion can cause confusion about treatment.
* Cultural differences between the doctors and the caregivers or patient can affect communication.
* In some cultures, it is customary to keep a life-threatening diagnosis from the patient and avoid talking about the disease.
* Sometimes it is up to the caregiver to tell the patient the truth about their health or about the terminal illness.
* This is stressful for the caregiver and only increases their feelings of loneliness and responsibility.
* Caregivers should be honest with the health care team about their cultural beliefs and concerns.

**The Caregiver’s Quality of Life**

* Family [caregivers](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=648947&version=Patient&language=English) usually begin caregiving without training and are expected to meet many demands without much help.
* A caregiver often neglects his or her own [quality of life](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=45417&version=Patient&language=English) by putting the patient's needs first.
* Health care providers watch for signs of caregiver [distress](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=454701&version=Patient&language=English) during the course of the patient's [cancer](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=45333&version=Patient&language=English) treatment.
* ****When caregiver strain affects the quality of caregiving, the patient's well-being is also affected. Helping the caregiver also helps the patient.
* Caring for a patient with cancer dramatically affects the caregiver’s quality of life in many areas.

#### **Psychological Issues**

* Psychological distress is the most common effect of caregiving on the caregiver's quality of life.
* Caring for a cancer patient is a difficult and [stressful](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=450122&version=Patient&language=English) job.
* Caregiver distress comes from the practical demands of the caregiver role as well the emotional ones, such as seeing the patient suffer.

**The Caregiver’s Quality of Life – continued**

* Family members seeing a loved one with cancer may feel as much or more distress than the patient does.
	+ Distress is usually worse when the cancer is advanced and the patient is no longer being treated to [cure](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=318813&version=Patient&language=English) the cancer.
* Caregivers who have health problems of their own or demands from other parts of their lives may enter the caregiving role already overwhelmed.
	+ For an older adult caregiver, problems that are a part of aging may make caregiving harder to handle.
* The caregiver's ability to [cope](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=454700&version=Patient&language=English) with distress may be affected by his or her personality type.
* Someone who is usually hopeful and positive may cope better with problems of caregiving.

#### **Physical Issues**

* Cancer patients often need a lot of physical help during their illness.
* ****This is physically demanding for the caregiver, who may need to help the patient with many activities during the day such as:
	+ Toilet use, eating, change positions in bed, patient transfers, using medical equipment.
* The amount of physical help a patient needs depends on the following:
	+ Ability of the patient to do normal [activities of daily living](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=430401&version=Patient&language=English) (ADL).
	+ The amount of [fatigue](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=321374&version=Patient&language=English) the patient has.
	+ The [stage](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=45885&version=Patient&language=English) of the cancer.
	+ The [symptoms](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=45022&version=Patient&language=English) and how bad they are.
	+ [Side effects](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=46580&version=Patient&language=English) of the cancer and the cancer treatments.
* As caregivers try to meet the physical demands of caregiving, they may not get enough rest and may not take care of their own health.
	+ Health problems the caregiver already has may become worse, or they may have new health problems.

**The Caregiver’s Quality of Life – continued**

#### **Social Issues**

* Caregivers often have less time to spend with friends and in the community as their days are filled with caring for the cancer patient.
* If there are problems in the relationship between the caregiver and the patient, the caregiver may feel even more alone.
* In the beginning, there may be a lot of support from friends.
	+ The caregiver may be able to continue working and keep up work relationships.
	+ When care continues for a long time, the caregiver may need to stop working and friends may call or visit less often.
	+ As caregivers struggle to meet the ongoing demands of caregiving, they may want more help from family and friends.
	+ Caregivers can find support in other places, such as caregiver groups and cancer organizations, where they can talk with other families.
	+ Some caregivers find it helpful to join a [support group](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=45917&version=Patient&language=English) or talk to a [counselor](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=688836&version=Patient&language=English), [psychologist](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=44716&version=Patient&language=English), pastor or other professional.

#### **Money Issues**

* The financial costs of cancer can be staggering.
* Families must pay insurance deductibles, copayments, and for services that are not covered by insurance.
* Some caregivers give up their jobs and income so they can stay home with the patient, which makes it harder to pay for everything.
* Caregivers who work may have less distress if they are able to take leave from work under the Family and Medical Leave Act (FMLA).
	+ FMLA applies to businesses with at least 50 employees. It allows employees to take time off from work for their own illness or a relative's serious medical [condition](http://www.cancer.gov/Common/PopUps/popDefinition.aspx?id=651193&version=Patient&language=English) without losing their jobs or benefits.
	+ Caregivers may take up to 12 weeks of leave.

**The Caregiver’s Quality of Life – continued**

**Spiritual Issues**

* Feelings of spiritual well-being may lower the caregiver’s stress.
* Keeping faith and finding meaning and hope have been shown to decrease the caregiver’s stress and mental health.
* Being at peace spiritually may help some caregiver’s be more helpful and more accepting of the cancer experience.

**Rewards of Caregiving**

* Caregivers become caregivers for many different reasons.
	+ Some feel it is natural to care for someone you love.
	+ Sometimes there are practical reasons such as limited insurance or resources to pay for home health care.
* Caring for a person with cancer causes many caregivers to look at life differently.
	+ They often reflect on the deeper things of life.
	+ They focus on what they value the most.
	+ They look for meaning as a way to cope.
	+ They may find they are stronger than they ever knew.
	+ They may have a better sense of self-worth and personal growth.
	+ They may feel closer to the patient and closer to God.

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