



TEN COMMANDMENTS OF GOOD LISTENING



1. **STOP TALKING**
You cannot listen if you are talking. Wait; your turn will come.
2. **PUT THE TALKER AT EASE**
Help him/her feel that he/she is free to talk. This is often called a “permissive, safe environment.”
3. **SHOW HIM/HER THAT YOU WANT TO LISTEN**
Look and act interested. Listen to understand, rather than to reply.
4. **REMOVE DISTRACTIONS**
Don’t doodle, tap, read or shuffle papers. Will it be quieter if you shut the door or turn down the radio?
5. **EMPATHIZE WITH HIM/HER**
Try to put yourself in his/her place so that you can see his/her point of view.
6. **BE PATIENT**
Allow plenty of time. Don’t interrupt. Don’t start for the door, or walk away, or make hand signals to hurry them along.
7. **HOLD YOUR TEMPER**
An angry person gets the wrong meaning from words and the anger inhibits active listening.
8. **GO EASY ON ARGUMENT AND CRITICISM**
This puts the talker on the defensive. He/she may “clam up” and get angry. Don’t argue: if you win, you lose, since they were unable to tell you their feelings and you learn nothing.
9. **ASK QUESTIONS**
This encourages him/her to expand his/her thoughts and shows you are listening. It helps them to develop points further.
10. **STOP TALKING!**
This is the first and last, because all other commandments depend on it. You just can’t do a good job of listening while you are talking.

**NATURE GAVE US TWO EARS, BUT ONLY ONE TONGUE,
WHICH IS A GENTLY REMINDER THAT WE SHOULD LISTEN
MORE THAN WE TALK!**

Fostering an Optimistic Outlook

While people tend toward being optimistic or pessimistic, optimism can be learned and practiced.

Being hopeful makes life under stress more bearable.

Hope can comfort and heal.

Having a hopeful outlook is believing that if one door to the future is closed, another door will open.





STRATEGIES TO PROMOTE HOPE

Hope and optimism are yours to manage and control. There are many ways to maintain hope that are listed below. Identify the strategies that will work the best for you and practice them regularly.

■ INVOLVING OTHERS

Surround yourself with others who are hopeful. HOPE IS CONTAGIOUS (so is hopelessness). Seek out people who believe in you and your ability to overcome difficulties.

Permit friends and family to help you with chores, meals and errands so you can save your energy for feeling better.

Remind family and friends involved in your life that you need to keep as much control as possible over daily decisions. Ask them to present you with choices rather than making decisions for you.

■ IMPROVING YOUR ATTITUDE

Look for silver linings. You have control over how you view the world and your situation. Identify positive things that may come from negative situations. This is not meant to deny unpleasant feelings, but is a way to begin to work through them.

Think positively to help build faith in yourself. Remember past accomplishments, particularly your strengths that got you through previous cancer treatments or other difficult experiences. Surround yourself with uplifting messages (like posters, pictures, magnets, hand-written notes) to inspire you to think positively.

Avoid getting stuck in self-pity. Remind yourself that cancer is a very common disease, not an unfair punishment. Currently,, there are over 9 million cancer survivors in the U.S. You are not alone.

Remind yourself that some changes and sacrifices are worthwhile if the treatment makes you better or lengthens your survival. Some cancer patients hope for an extended remission if cure is not possible.

■ **HANDLING YOUR EMOTIONS**

Talk about your feelings. Attend support groups or get emotional support from others with whom you are close. Keep a diary or audio tape of your experiences and feelings.

Remember that unpleasant feelings such as anger, fear, and disappointment are normal and expected. Look for safe and healthy ways to relieve bad feelings. Feeling hopeless at times is also normal. Hope and hopelessness can both be present when a family is facing cancer.

Practice letting go of worrying about what could happen in the future so that these fears do not prevent you from enjoying today.

Talk to a mental health professional to help you adjust to living with cancer, especially if you are experiencing a reaction like depression.

■ **FINDING ACTIVITIES THAT FOSTER HOPE**

Participate in activities that bring comfort or promote hope such as praying, meditating, visiting with clergy, listening to uplifting music, or reading inspirational books. Continue hobbies that you have enjoyed in the past or start a new hobby that has always interested you. Make adjustments if you have physical limitations: hike a simple trail instead of a mountain trail; “garden” plants indoors, watch golf or tennis on television.

Try to do activities that keep you from feeling like your life is totally taken up by cancer. It is VERY IMPORTANT to choose your activities wisely and pace yourself. Some activities will increase your energy, others may drain it. Strive for a balance of keeping active, but getting the rest you need.

Set aside time each day to do things that will decrease stress such as deep breathing, head-to-toe relaxation, meditation, etc. Many books and tapes are available to teach you how. Find one that appeals to you. Avoid unhealthy ways of dealing with stress such as misusing alcohol and drugs, overeating, or avoiding activities and people.

Practice a healthy lifestyle: eat a balanced diet, exercise, get enough sleep and arrange for rest periods during the day.

Seek physical comforts such as closeness to someone dear, touches, hugs, massages, or warm bubble baths.

Find activities that make you laugh (books, movies, playing with children or pets). Humor can be very helpful.

Make time to be involved with someone or something outside of yourself: family, friends, pets, plants, or hobbies.

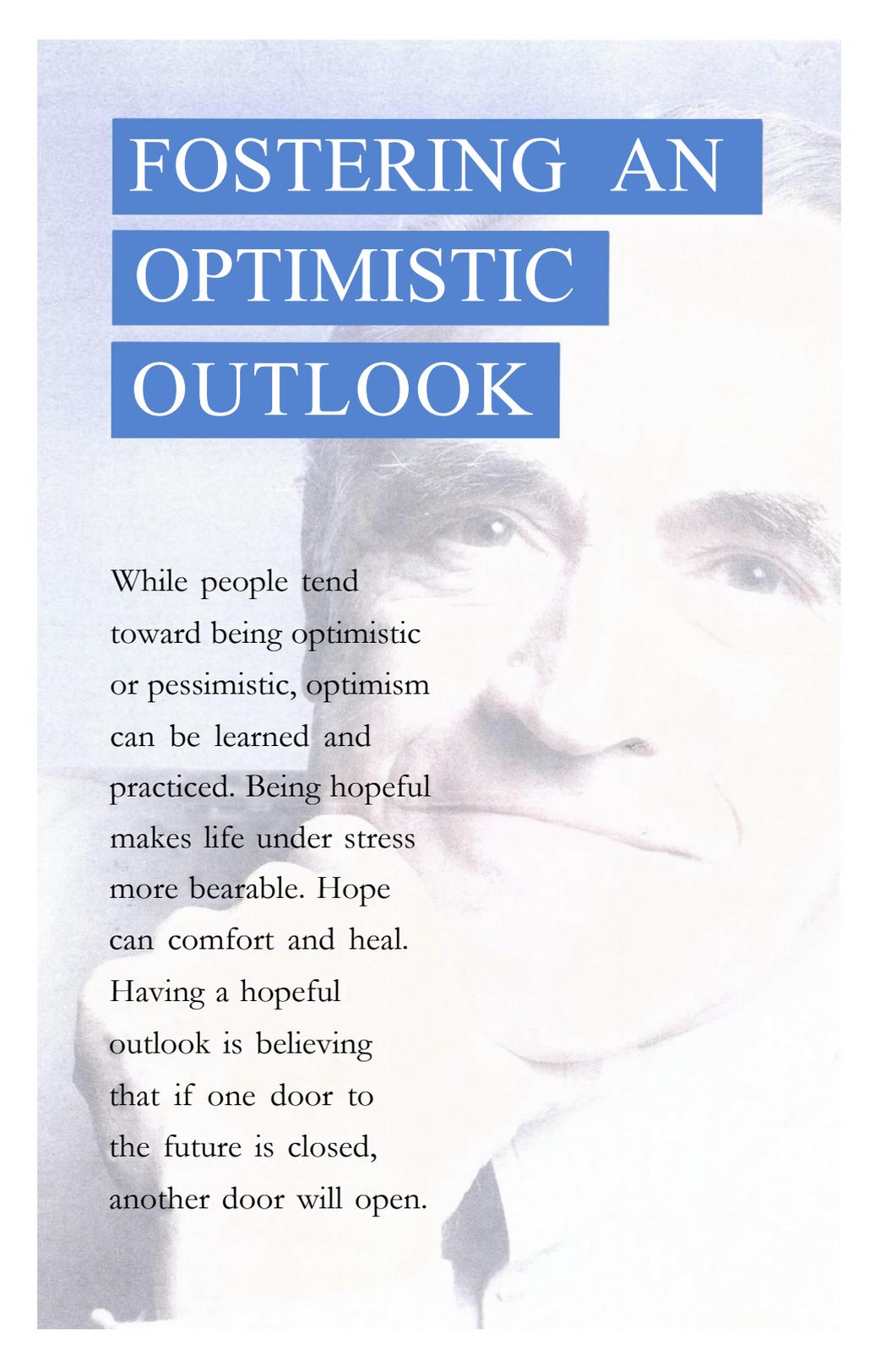
Focus on small joys that are reason for celebration: the brilliant colors of fall, a soft puppy, birds singing, the taste of a favorite food, the warmth of the sun, the smell of a favorite perfume, or watching a sunset.

■ CONCLUSIONS

Identify your sources of hope (spiritual beliefs, family, inner self, humor, etc.) and use them to look at your world more positively. Perhaps most importantly, **LIVE IN THE PRESENT**. Try to appreciate every moment and every day you have.



(c) 2005, 2001 All Rights Reserved
Ann Schafenacker RN, MSN
Julie Walker RN, MSN
Laurel Northouse PhD, RN
University of Michigan School of Nursing
400 North Ingalls, Ann Arbor, MI 48109
(734) 615-4016 or lnortho@umich.edu



FOSTERING AN OPTIMISTIC OUTLOOK

While people tend toward being optimistic or pessimistic, optimism can be learned and practiced. Being hopeful makes life under stress more bearable. Hope can comfort and heal. Having a hopeful outlook is believing that if one door to the future is closed, another door will open.



STRATEGIES TO PROMOTE HOPE

Hope and optimism are yours to manage and control. How you involve other people, your attitude about your situation, how you handle your feelings and what activities you pursue, all influence your sense of hope.

INVOLVING OTHERS

Surround yourself with others who are hopeful.

HOPE IS CONTAGIOUS (so is hopelessness). Seek out people who believe in you and your ability to overcome difficulties.

Permit friends and family to help you with chores, meals and errands so you can save your energy for getting well.

Remind family and friends involved in your life that you need to keep as much control as possible over daily decisions. Ask them to present you with choices rather than making decisions for you.

IMPROVING YOUR ATTITUDE

Look for silver linings. You have control over how you view the world and your situation. Identify positive things that may come from negative situations. This is not meant to deny unpleasant feelings, but is a way to begin to work through them.

Think positively to help build faith in yourself. Remember past accomplishments, particularly your strengths that got you through previous cancer treatments or other difficult experiences. Surround yourself with positive messages (posters, pictures, magnets, handwritten notes) to inspire you.

Avoid getting stuck in self-pity. Remind yourself that cancer is a fact of life, not an unfair punishment, and believe that you can adapt and cope with cancer treatment.

Remind yourself that some changes and sacrifices are worthwhile if the treatment makes you better or lengthens your survival. Some cancer patients may hope for an extended remission if cure is not possible.

Identify your personal and family strengths such as endurance, courage and patience. Focus on what you have, not on what you don't have. Start a "Gratitude Journal" recording 2 or 3 things you are grateful for each day.

Set realistic goals for the future including immediate and long-term plans. Reset goals when necessary. Break down goals into small steps that are easy to achieve and give you a sense of accomplishment.

HANDLING YOUR EMOTIONS

Talk about your feelings. Attend support groups or get emotional support from others with whom you are close. Keep a diary or audio tape of your experiences and feelings.

Remember that unpleasant feelings such as anger, fear and disappointment are normal and expected. Look for safe and healthy ways to relieve bad feelings. Feeling hopeless at times is also normal. Hope and hopelessness can both be present when a person is fighting cancer.

Practice letting go of worrying about what could happen in the future so that these fears do not prevent you from enjoying today.

Talk to a mental health professional to help you adjust to living with cancer, especially if you are experiencing a reaction like depression.

FINDING ACTIVITIES THAT FOSTER HOPE

Participate in activities that bring comfort or promote hope: praying, meditating, visiting with clergy, listening to uplifting music, or reading inspirational books. Continue hobbies that you have enjoyed in the past or start a new hobby that has always interested you. Make adjustments if necessary for physical reasons: garden plants indoors, watch golf or tennis on television, hike a simple trail instead of mountain climbing.

Try to do activities that keep you from feeling like your life is totally taken up by cancer. It is VERY IMPORTANT to choose

your activities wisely and pace yourself. Some activities will increase your energy, others may drain it. Strive for a balance of keeping active, but getting the rest you need.

Set aside time each day to do things that will decrease stress such as deep breathing, head-to-toe relaxation, meditation, etc. Many books and tapes are available to teach you how. Find one that appeals to you. Avoid unhealthy ways of dealing with stress such as misusing alcohol and drugs, overeating, and avoiding activities and people.

Practice a healthy lifestyle: eat a balanced diet, exercise, get enough sleep and arrange for rest periods during the day.

Seek physical comforts such as closeness to someone dear, touches, hugs, massages, warm bubble baths.

Find activities that make you laugh (books, movies, playing with children or pets). Humor can be very helpful.

Make time to be involved with someone or something outside of yourself: family, friends, pets, plants, hobbies.

Focus on small joys that are reason for celebration: the brilliant colors of fall, a soft puppy, birds singing, the taste of a favorite food, the warmth of the sun, the smell of a favorite perfume, watching a sunset.

CONCLUSIONS

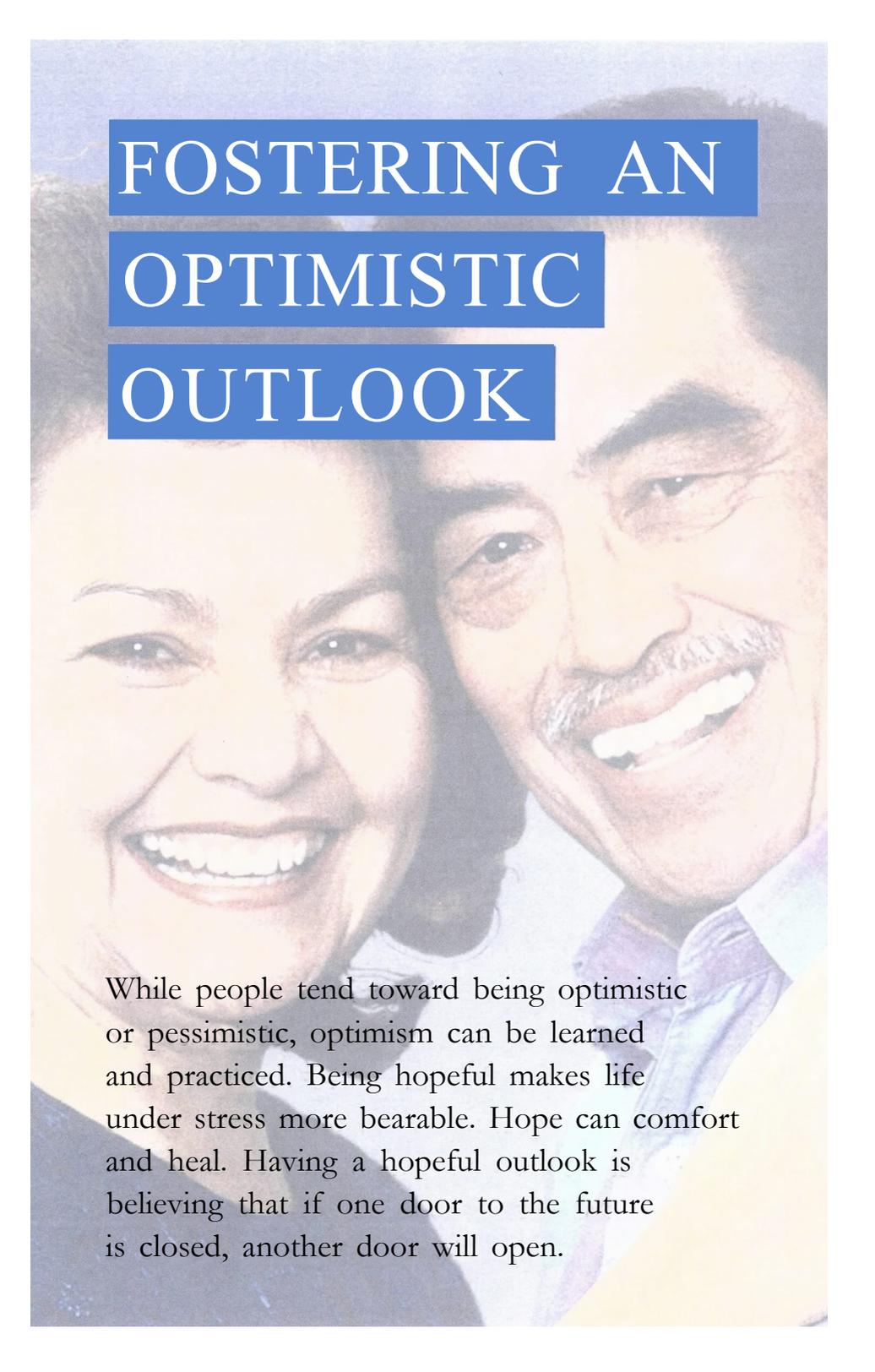
Identify your sources of hope (spiritual beliefs, family, inner self, humor, etc.) and use them to look at your world more positively. Perhaps most importantly, LIVE IN THE PRESENT. Try to appreciate every moment and every day you have.



HELPING OTHERS THROUGH RESEARCH

(c) 2001 All Rights Reserved
Ann Schafenacker RN, MSN
Julie Walker RN, MSN
Laurel Northouse PhD, RN
University of Michigan School of Nursing
400 North Ingalls, Ann Arbor, MI 48109
(734) 615-4016 or lnortho@umich.edu
Design: UM Comprehensive Cancer Center, HMRL

This brochure was developed with support from the Mary Lou Willard French Endowment.



FOSTERING AN OPTIMISTIC OUTLOOK

While people tend toward being optimistic or pessimistic, optimism can be learned and practiced. Being hopeful makes life under stress more bearable. Hope can comfort and heal. Having a hopeful outlook is believing that if one door to the future is closed, another door will open.



STRATEGIES TO PROMOTE HOPE

Hope and optimism are yours to manage and control. How you involve other people, your attitude about your situation, how you handle your feelings and what activities you pursue, all influence your sense of hope.

INVOLVING OTHERS

Surround yourself with others who are hopeful.

HOPE IS CONTAGIOUS (so is hopelessness). Seek out people who believe in you and your ability to overcome difficulties.

Permit friends and family to help you with chores, meals and errands so you can save your energy for getting well.

Remind family and friends involved in your life that you need to keep as much control as possible over daily decisions. Ask them to present you with choices rather than making decisions for you.

IMPROVING YOUR ATTITUDE

Look for silver linings. You have control over how you view the world and your situation. Identify positive things that may come from negative situations. This is not meant to deny unpleasant feelings, but is a way to begin to work through them.

Think positively to help build faith in yourself. Remember past accomplishments, particularly your strengths that got you through previous cancer treatments or other difficult experiences. Surround yourself with positive messages (posters, pictures, magnets, hand-written notes) to inspire you.

Avoid getting stuck in self-pity. Remind yourself that cancer is a fact of life, not an unfair punishment, and believe that you can adapt and cope with cancer treatment.

Remind yourself that some changes and sacrifices are worthwhile if the treatment makes you better or lengthens your survival. Some cancer patients may hope for an extended remission if cure is not possible.

Identify your personal and family strengths such as endurance, courage and patience. Focus on what you have, not on what you don't have. Start a "Gratitude Journal" recording 2 or 3 things you are grateful for each day.

Set realistic goals for the future including immediate and long-term plans. Reset goals when necessary. Break down goals into small steps that are easy to achieve and give you a sense of accomplishment.

HANDLING YOUR EMOTIONS

Talk about your feelings. Attend support groups or get emotional support from others with whom you are close. Keep a diary or audio tape of your experiences and feelings.

Remember that unpleasant feelings such as anger, fear and disappointment are normal and expected. Look for safe and healthy ways to relieve bad feelings. Feeling hopeless at times is also normal. Hope and hopelessness can both be present when a person is fighting cancer.

Practice letting go of worrying about what could happen in the future so that these fears do not prevent you from enjoying today.

Talk to a mental health professional to help you adjust to living with cancer, especially if you are experiencing a reaction like depression.

FINDING ACTIVITIES THAT FOSTER HOPE

Participate in activities that bring comfort or promote hope: praying, meditating, visiting with clergy, listening to uplifting music, or reading inspirational books. Continue hobbies that you have enjoyed in the past or start a new hobby that has always interested you. Make adjustments if necessary for physical reasons: garden plants indoors, watch golf or tennis on television, hike a simple trail instead of mountain climbing.

Try to do activities that keep you from feeling like your life is totally taken up by cancer. It is VERY IMPORTANT to choose

your activities wisely and pace yourself. Some activities will increase your energy, others may drain it. Strive for a balance of keeping active, but getting the rest you need.

Set aside time each day to do things that will decrease stress such as deep breathing, head-to-toe relaxation, meditation, etc. Many books and tapes are available to teach you how. Find one that appeals to you. Avoid unhealthy ways of dealing with stress such as misusing alcohol and drugs, overeating, and avoiding activities and people.

Practice a healthy lifestyle: eat a balanced diet, exercise, get enough sleep and arrange for rest periods during the day.

Seek physical comforts such as closeness to someone dear, touches, hugs, massages, warm bubble baths.

Find activities that make you laugh (books, movies, playing with children or pets). Humor can be very helpful.

Make time to be involved with someone or something outside of yourself: family, friends, pets, plants, hobbies.

Focus on small joys that are reason for celebration: the brilliant colors of fall, a soft puppy, birds singing, the taste of a favorite food, the warmth of the sun, the smell of a favorite perfume, watching a sunset.

CONCLUSIONS

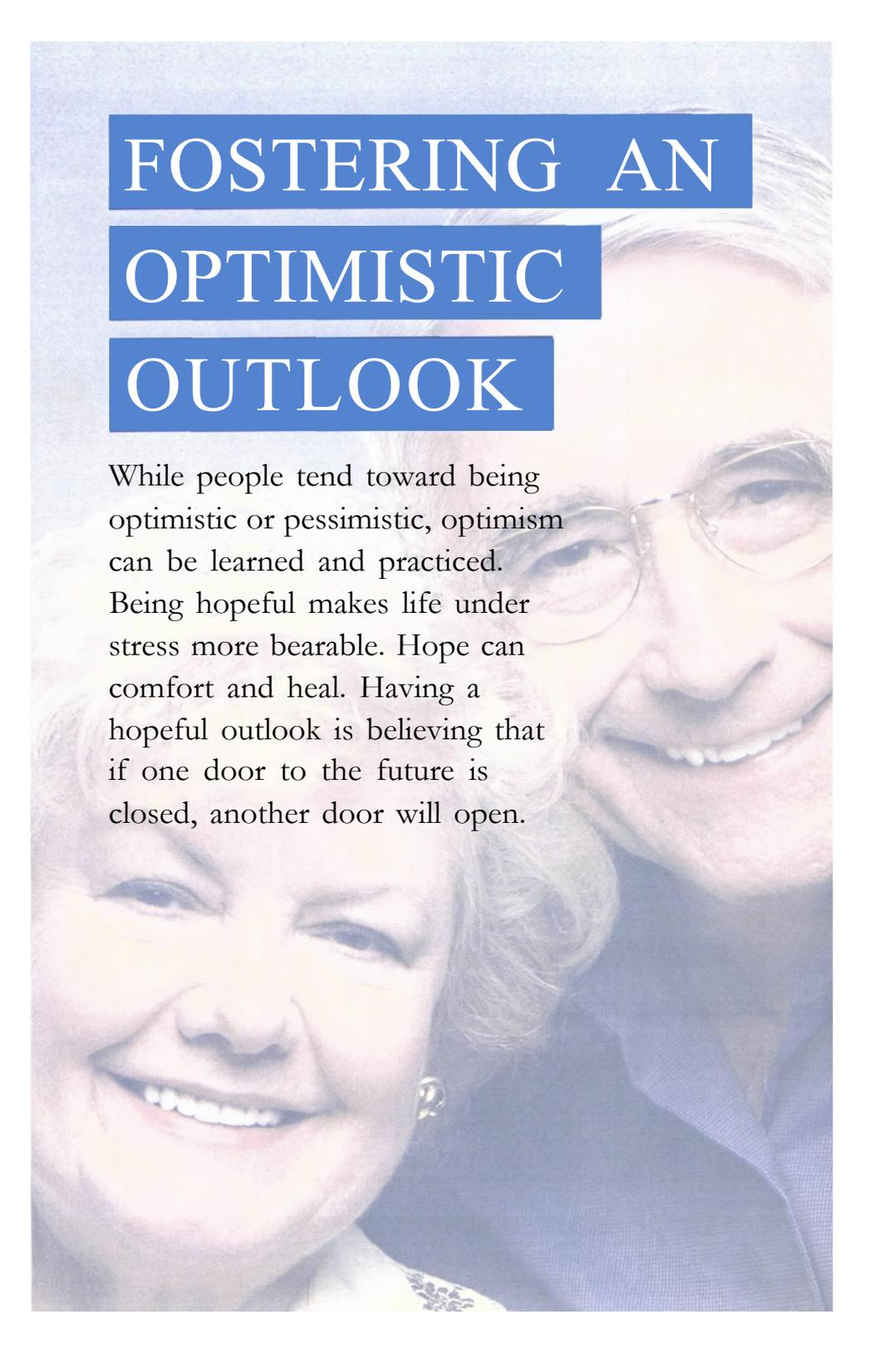
Identify your sources of hope (spiritual beliefs, family, inner self, humor, etc.) and use them to look at your world more positively. Perhaps most importantly, LIVE IN THE PRESENT. Try to appreciate every moment and every day you have.



HELPING OTHERS THROUGH RESEARCH

(c) 2001 All Rights Reserved
Ann Schafenacker RN, MSN
Julie Walker RN, MSN
Laurel Northouse PhD, RN
University of Michigan School of Nursing
400 North Ingalls, Ann Arbor, MI 48109
(734) 615-4016 or lnortho@umich.edu
Design: UM Comprehensive Cancer Center; HMRL

This brochure was developed with support from the Mary Lou Willard French Endowment.



FOSTERING AN OPTIMISTIC OUTLOOK

While people tend toward being optimistic or pessimistic, optimism can be learned and practiced. Being hopeful makes life under stress more bearable. Hope can comfort and heal. Having a hopeful outlook is believing that if one door to the future is closed, another door will open.



STRATEGIES TO PROMOTE HOPE

Hope and optimism are yours to manage and control. How you involve other people, your attitude about your situation, how you handle your feelings and what activities you pursue, all influence your sense of hope.

INVOLVING OTHERS

Surround yourself with others who are hopeful.

HOPE IS CONTAGIOUS (so is hopelessness). Seek out people who believe in you and your ability to overcome difficulties.

Permit friends and family to help you with chores, meals and errands so you can save your energy for getting well.

Remind family and friends involved in your life that you need to keep as much control as possible over daily decisions. Ask them to present you with choices rather than making decisions for you.

IMPROVING YOUR ATTITUDE

Look for silver linings. You have control over how you view the world and your situation. Identify positive things that may come from negative situations. This is not meant to deny unpleasant feelings, but is a way to begin to work through them.

Think positively to help build faith in yourself. Remember past accomplishments, particularly your strengths that got you through previous cancer treatments or other difficult experiences. Surround yourself with positive messages (posters, pictures, magnets, hand-written notes) to inspire you.

Avoid getting stuck in self-pity. Remind yourself that cancer is a fact of life, not an unfair punishment, and believe that you can adapt and cope with cancer treatment.

Remind yourself that some changes and sacrifices are worthwhile if the treatment makes you better or lengthens your survival. Some cancer patients may hope for an extended remission if cure is not possible.

Identify your personal and family strengths such as endurance, courage and patience. Focus on what you have, not on what you don't have. Start a "Gratitude Journal" recording 2 or 3 things you are grateful for each day.

Set realistic goals for the future including immediate and long-term plans. Reset goals when necessary. Break down goals into small steps that are easy to achieve and give you a sense of accomplishment.

HANDLING YOUR EMOTIONS

Talk about your feelings. Attend support groups or get emotional support from others with whom you are close. Keep a diary or audio tape of your experiences and feelings.

Remember that unpleasant feelings such as anger, fear and disappointment are normal and expected. Look for safe and healthy ways to relieve bad feelings. Feeling hopeless at times is also normal. Hope and hopelessness can both be present when a person is fighting cancer.

Practice letting go of worrying about what could happen in the future so that these fears do not prevent you from enjoying today.

Talk to a mental health professional to help you adjust to living with cancer, especially if you are experiencing a reaction like depression.

FINDING ACTIVITIES THAT FOSTER HOPE

Participate in activities that bring comfort or promote hope: praying, meditating, visiting with clergy, listening to uplifting music, or reading inspirational books. Continue hobbies that you have enjoyed in the past or start a new hobby that has always interested you. Make adjustments if necessary for physical reasons: garden plants indoors, watch golf or tennis on television, hike a simple trail instead of mountain climbing.

Try to do activities that keep you from feeling like your life is totally taken up by cancer. It is VERY IMPORTANT to choose

your activities wisely and pace yourself. Some activities will increase your energy, others may drain it. Strive for a balance of keeping active, but getting the rest you need.

Set aside time each day to do things that will decrease stress such as deep breathing, head-to-toe relaxation, meditation, etc. Many books and tapes are available to teach you how. Find one that appeals to you. Avoid unhealthy ways of dealing with stress such as misusing alcohol and drugs, overeating, and avoiding activities and people.

Practice a healthy lifestyle: eat a balanced diet, exercise, get enough sleep and arrange for rest periods during the day.

Seek physical comforts such as closeness to someone dear, touches, hugs, massages, warm bubble baths.

Find activities that make you laugh (books, movies, playing with children or pets). Humor can be very helpful.

Make time to be involved with someone or something outside of yourself: family, friends, pets, plants, hobbies.

Focus on small joys that are reason for celebration: the brilliant colors of fall, a soft puppy, birds singing, the taste of a favorite food, the warmth of the sun, the smell of a favorite perfume, watching a sunset.

CONCLUSIONS

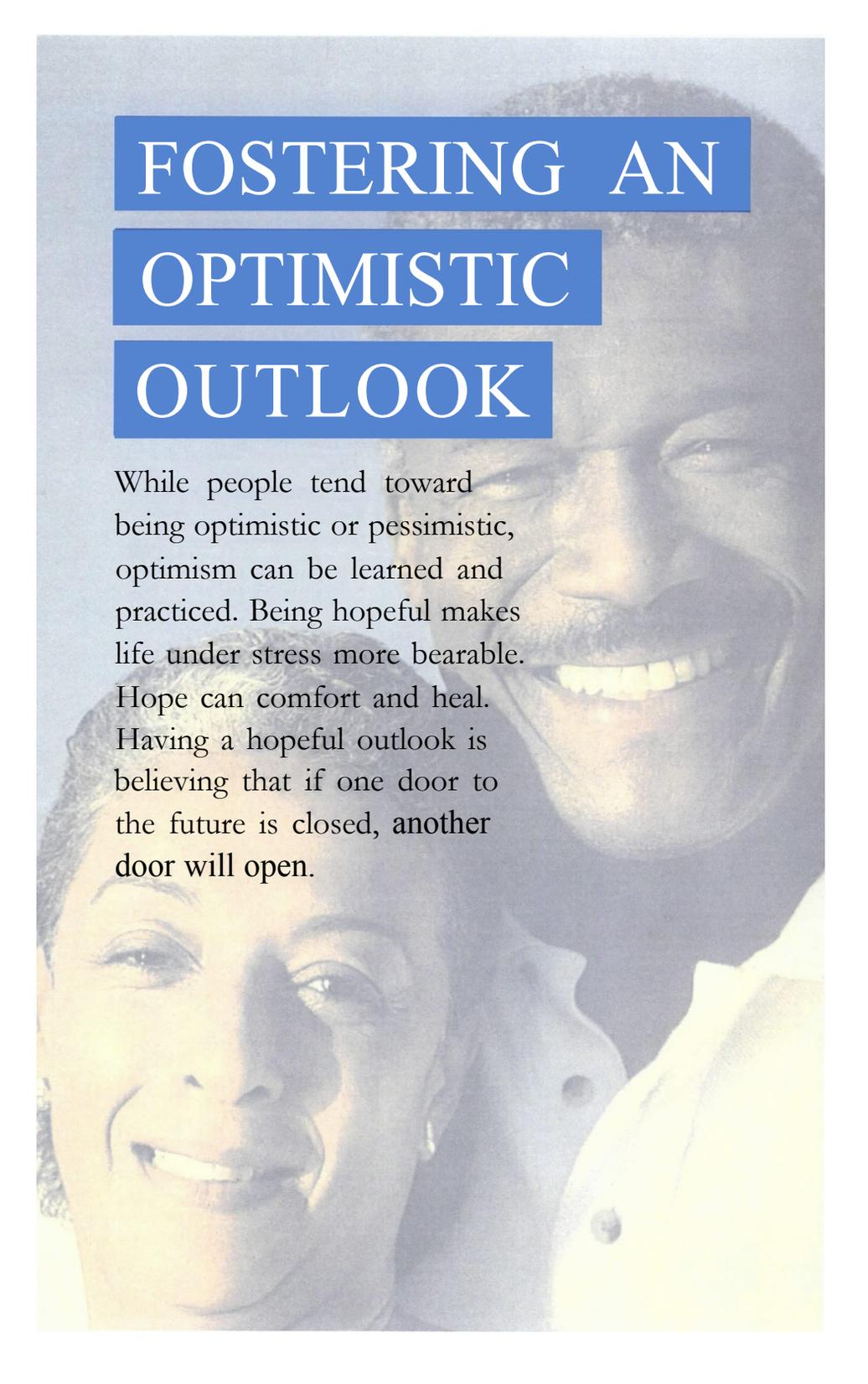
Identify your sources of hope (spiritual beliefs, family, inner self, humor, etc.) and use them to look at your world more positively. Perhaps most importantly, LIVE IN THE PRESENT. Try to appreciate every moment and every day you have.



HELPING OTHERS THROUGH RESEARCH

(c) 2001 All Rights Reserved
Ann Schafenacker RN, MSN
Julie Walker RN, MSN
Laurel Northouse PhD, RN
University of Michigan School of Nursing
400 North Ingalls, Ann Arbor, MI 48109
(734) 615-4016 or lnortho@umich.edu
Design: UM Comprehensive Cancer Center, HMRL

This brochure was developed with support from the Mary Lou Willard French Endowment.



FOSTERING AN OPTIMISTIC OUTLOOK

While people tend toward being optimistic or pessimistic, optimism can be learned and practiced. Being hopeful makes life under stress more bearable. Hope can comfort and heal. Having a hopeful outlook is believing that if one door to the future is closed, another door will open.



STRATEGIES TO PROMOTE HOPE

Hope and optimism are yours to manage and control. How you involve other people, your attitude about your situation, how you handle your feelings and what activities you pursue, all influence your sense of hope.

INVOLVING OTHERS

Surround yourself with others who are hopeful.

HOPE IS CONTAGIOUS (so is hopelessness). Seek out people who believe in you and your ability to overcome difficulties.

Permit friends and family to help you with chores, meals and errands so you can save your energy for getting well.

Remind family and friends involved in your life that you need to keep as much control as possible over daily decisions. Ask them to present you with choices rather than making decisions for you.

IMPROVING YOUR ATTITUDE

Look for silver linings. You have control over how you view the world and 'your situation. Identify positive things that may come from negative situations. This is not meant to deny unpleasant feelings, but is a way to begin to work through them.

Think positively to help build faith in yourself. Remember past accomplishments, particularly your strengths that got you through previous cancer treatments or other difficult experiences. Surround yourself with positive messages (posters, pictures, magnets, hand-written notes) to inspire you.

Avoid getting stuck in self-pity. Remind yourself that cancer is a fact of life, not an unfair punishment, and believe that you can adapt and cope with cancer treatment.

Remind yourself that some changes and sacrifices are worthwhile if the treatment makes you better or lengthens your survival. Some cancer patients may hope for an extended remission if cure is not possible.

Identify your personal and family strengths such as endurance, courage and patience. Focus on what you have, not on what you don't have. Start a "Gratitude Journal" recording 2 or 3 things you are grateful for each day.

Set realistic goals for the future including immediate and long-term plans. Reset goals when necessary. Break down goals into small steps that are easy to achieve and give you a sense of accomplishment.

HANDLING YOUR EMOTIONS

Talk about your feelings. Attend support groups or get emotional support from others with whom you are close. Keep a diary or audio tape of your experiences and feelings.

Remember that unpleasant feelings such as anger, fear and disappointment are normal and expected. Look for safe and healthy ways to relieve bad feelings. Feeling hopeless at times is also normal. Hope and hopelessness can both be present when a person is fighting cancer.

Practice letting go of worrying about what could happen in the future so that these fears do not prevent you from enjoying today.

Talk to a mental health professional to help you adjust to living with cancer, especially if you are experiencing a reaction like depression.

FINDING ACTIVITIES THAT FOSTER HOPE

Participate in activities that bring comfort or promote hope: praying, meditating, visiting with clergy, listening to uplifting music, or reading inspirational books. Continue hobbies that you have enjoyed in the past or start a new hobby that has always interested you. Make adjustments if necessary for physical reasons: garden plants indoors, watch golf or tennis on television, hike a simple trail instead of mountain climbing.

Try to do activities that keep you from feeling like your life is totally taken up by cancer. It is VERY IMPORTANT to choose

your activities wisely and pace yourself. Some activities will increase your energy, others may drain it. Strive for a balance of keeping active, but getting the rest you need.

Set aside time each day to do things that will decrease stress such as deep breathing, head-to-toe relaxation, meditation, etc. Many books and tapes are available to teach you how. Find one that appeals to you. Avoid unhealthy ways of dealing with stress such as misusing alcohol and drugs, overeating, and avoiding activities and people.

Practice a healthy lifestyle: eat a balanced diet, exercise, get enough sleep and arrange for rest periods during the day.

Seek physical comforts such as closeness to someone dear, touches, hugs, massages, warm bubble baths.

Find activities that make you laugh (books, movies, playing with children or pets). Humor can be very helpful.

Make time to be involved with someone or something outside of yourself: family, friends, pets, plants, hobbies.

Focus on small joys that are reason for celebration: the brilliant colors of fall, a soft puppy, birds singing, the taste of a favorite food, the warmth of the sun, the smell of a favorite perfume, watching a sunset.

CONCLUSIONS

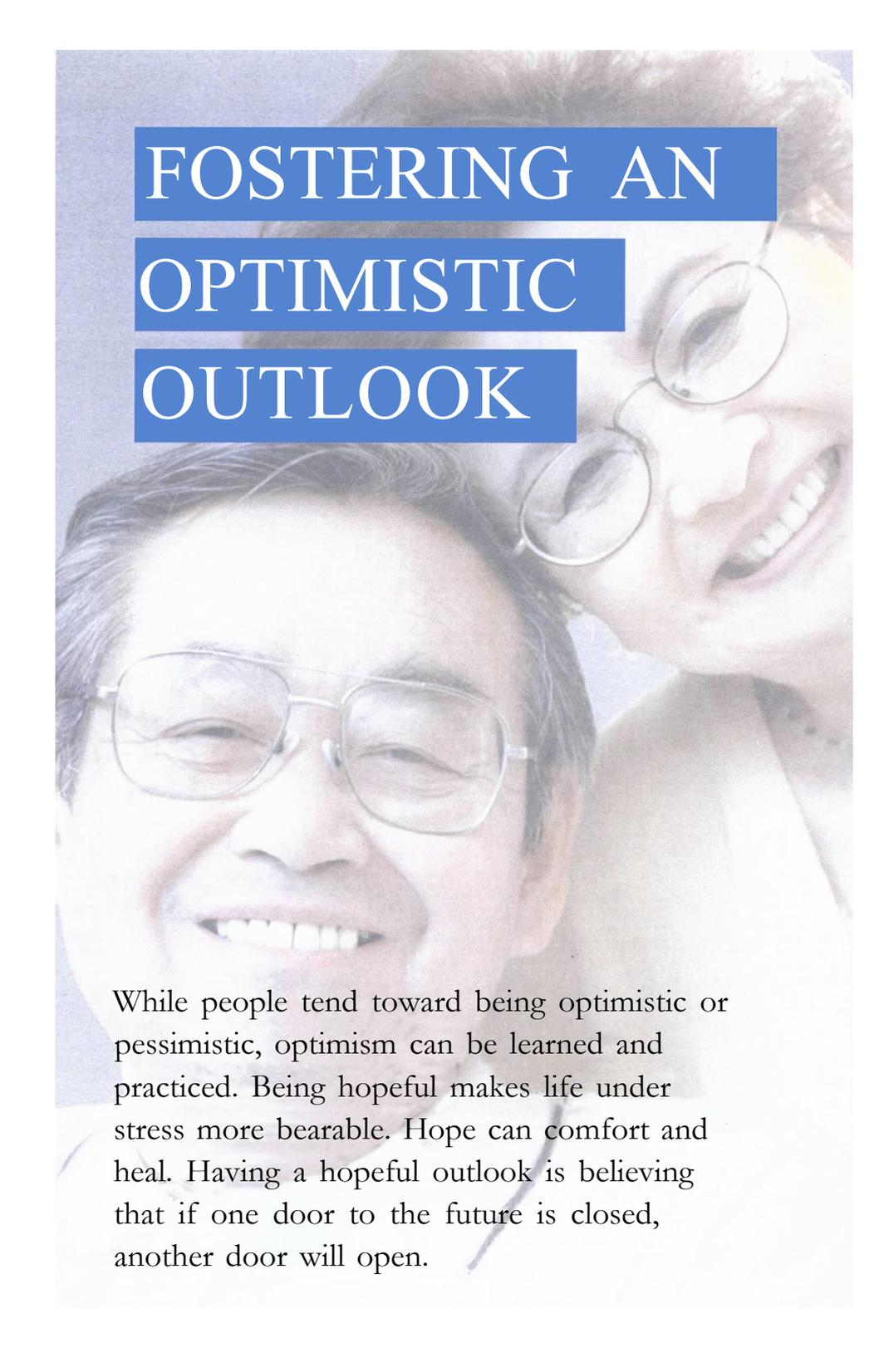
Identify your sources of hope (spiritual beliefs, family, inner self, humor, etc.) and use them to look at your world more positively. Perhaps most importantly, LIVE IN THE PRESENT. Try to appreciate every moment and every day you have.



HELPING OTHERS THROUGH RESEARCH

(c) 2001 All Rights Reserved
Ann Schafenacker RN, MSN
Julie Walker RN, MSN
Laurel Northouse PhD, RN
University of Michigan School of Nursing
400 North Ingalls, Ann Arbor, MI 48109
(734) 615-4016 or lnortho@umich.edu
Design: UM Comprehensive Cancer Center, HMRL

This brochure was developed with support from the Mary Lou Willard French Endowment.



FOSTERING AN OPTIMISTIC OUTLOOK

While people tend toward being optimistic or pessimistic, optimism can be learned and practiced. Being hopeful makes life under stress more bearable. Hope can comfort and heal. Having a hopeful outlook is believing that if one door to the future is closed, another door will open.



STRATEGIES TO PROMOTE HOPE

Hope and optimism are yours to manage and control. How you involve other people, your attitude about your situation, how you handle your feelings and what activities you pursue, all influence your sense of hope.

INVOLVING OTHERS

Surround yourself with others who are hopeful.

HOPE IS CONTAGIOUS (so is hopelessness). Seek out people who believe in you and your ability to overcome difficulties.

Permit friends and family to help you with chores, meals and errands so you can save your energy for getting well.

Remind family and friends involved in your life that you need to keep as much control as possible over daily decisions. Ask them to present you with choices rather than making decisions for you.

IMPROVING YOUR ATTITUDE

Look for silver linings. You have control over how you view the world and your situation. Identify positive things that may come from negative situations. This is not meant to deny unpleasant feelings, but is a way to begin to work through them.

Think positively to help build faith in yourself. Remember past accomplishments, particularly your strengths that got you through previous cancer treatments or other difficult experiences. Surround yourself with positive messages (posters, pictures, magnets, hand-written notes) to inspire you.

Avoid getting stuck in self-pity. Remind yourself that cancer is a fact of life, not an unfair punishment, and believe that you can adapt and cope with cancer treatment.

Remind yourself that some changes and sacrifices are worthwhile if the treatment makes you better or lengthens your survival. Some cancer patients may hope for an extended remission if cure is not possible.

Identify your personal and family strengths such as endurance, courage and patience. Focus on what you have, not on what you don't have. Start a "Gratitude Journal" recording 2 or 3 things you are grateful for each day.

Set realistic goals for the future including immediate and long-term plans. Reset goals when necessary. Break down goals into small steps that are easy to achieve and give you a sense of accomplishment.

HANDLING YOUR EMOTIONS

Talk about your feelings. Attend support groups or get emotional support from others with whom you are close. Keep a diary or audio tape of your experiences and feelings.

Remember that unpleasant feelings such as anger, fear and disappointment are normal and expected. Look for safe and healthy ways to relieve bad feelings. Feeling hopeless at times is also normal. Hope and hopelessness can both be present when a person is fighting cancer.

Practice letting go of worrying about what could happen in the future so that these fears do not prevent you from enjoying today.

Talk to a mental health professional to help you adjust to living with cancer, especially if you are experiencing a reaction like depression.

FINDING ACTIVITIES THAT FOSTER HOPE

Participate in activities that bring comfort or promote hope: praying, meditating, visiting with clergy, listening to uplifting music, or reading inspirational books. Continue hobbies that you have enjoyed in the past or start a new hobby that has always interested you. Make adjustments if necessary for physical reasons: garden plants indoors, watch golf or tennis on television, hike a simple trail instead of mountain climbing.

Try to do activities that keep you from feeling like your life is totally taken up by cancer. It is VERY IMPORTANT to choose

your activities wisely and pace yourself. Some activities will increase your energy, others may drain it. Strive for a balance of keeping active, but getting the rest you need.

Set aside time each day to do things that will decrease stress such as deep breathing, head-to-toe relaxation, meditation, etc. Many books and tapes are available to teach you how. Find one that appeals to you. Avoid unhealthy ways of dealing with stress such as misusing alcohol and drugs, overeating, and avoiding activities and people.

Practice a healthy lifestyle: eat a balanced diet, exercise, get enough sleep and arrange for rest periods during the day.

Seek physical comforts such as closeness to someone dear, touches, hugs, massages, warm bubble baths.

Find activities that make you laugh (books, movies, playing with children or pets). Humor can be very helpful.

Make time to be involved with someone or something outside of yourself: family, friends, pets, plants, hobbies.

Focus on small joys that are reason for celebration: the brilliant colors of fall, a soft puppy, birds singing, the taste of a favorite food, the warmth of the sun, the smell of a favorite perfume, watching a sunset.

CONCLUSIONS

Identify your sources of hope (spiritual beliefs, family, inner self, humor, etc.) and use them to look at your world more positively. Perhaps most importantly, LIVE IN THE PRESENT. Try to appreciate every moment and every day you have.



HELPING OTHERS THROUGH RESEARCH

(c) 2001 All Rights Reserved
Ann Schafenacker RN, MSN
Julie Walker RN, MSN
Laurel Northouse PhD, RN
University of Michigan School of Nursing
400 North Ingalls, Ann Arbor, MI 48109
(734) 615-4016 or lnortho@umich.edu
Design: UM Comprehensive Cancer Center, HMRL

This brochure was developed with support from the Mary Lou Willard French Endowment.

Eating Hints

FOR CANCER PATIENTS

Before, During & After Treatment



NATIONAL INSTITUTES OF HEALTH

National Cancer Institute



Acknowledgments

The National Cancer Institute would like to thank the numerous health professionals and patients nationwide who have assisted with and contributed to the development and review of this publication.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health



Eating Hints

FOR CANCER PATIENTS

Before, During
& After
Treatment

NATIONAL INSTITUTES OF HEALTH
National Cancer Institute



Table of Contents



About This Booklet	1
How <i>Eating Hints</i> for Cancer Patients is Organized	1
How To Use This Booklet	3
Before Treatment Begins	4
Nutrition Recommendations Can Be Different	
for Cancer Patients	5
Preparing Yourself for Cancer Treatment	6
Think Positively	6
Eat a Healthy Diet	6
Plan Ahead	7
Managing Eating Problems During Treatment	8
Coping With Side Effects	10
Loss of Appetite	10
Weight Loss	13
Weight Gain	17
Sore Mouth or Throat	18
Dry Mouth	21
Dental and Gum Problems	22
Changed Sense of Taste or Smell	22
Nausea	24
Vomiting	26
Diarrhea	27
Lactose Intolerance	29
Constipation	31
Fatigue and Depression	33
Special Notes for Caregivers	36
After Cancer Treatment Ends	37
Ways To Get Back Into Eating	38

(continued)

Recipes

Banana Milkshake (<i>if you experience appetite loss</i>).....	12
Fortified Milk (<i>if you are losing weight</i>).....	14
High-Protein Milkshake (<i>if you are losing weight</i>).....	15
Peanut Butter Snack Spread (<i>if you are losing weight</i>).....	16
Fruit and Cream (<i>if you have a sore mouth or throat</i>).....	19
Milk-Free Double Chocolate Pudding (<i>if you experience lactose intolerance</i>)....	30
Apple/Prune Sauce (<i>if you have constipation</i>).....	32

Special Issues

Commercial Products to Improve Nutrition	11
Special Diets for Special Needs	29
Preventing Food-Borne Illness	34
Extra Vitamins and Minerals — Will They Help?	34
What About Alternative Therapies?	35

Figure and Tables

Table 1. How Cancer Treatments Can Affect Eating	40
Table 2. Examples of Clear Liquids	42
Table 3. Examples of Full-Liquid Foods	43
Table 4. Quick & Easy Snacks	44
Table 5. How to Increase Calories	45
Table 6. How to Increase Protein	48
Keeping Track of Side Effects	51

Glossary 52

Resources 56

Organizations	56
Print Materials	57



About This Booklet

Your diet is an important part of your treatment for cancer. Eating the right kinds of foods before, during, and after your treatment can help you feel better and stay stronger.

The National Cancer Institute (NCI) has prepared this booklet to help you learn about your diet needs during treatment and to help you cope with side effects that may affect eating. It is designed for cancer patients and their families and other caregivers. The information here has been gathered from many sources and reflects the tried-and-true experience of cancer patients and the doctors, nurses, and dietitians who work with them.

How *Eating Hints for Cancer Patients* Is Organized

People experience many different emotions and physical reactions before, during, and after cancer treatment. Their desire for information varies greatly, too. Some may want to read everything they can get their hands on and talk to everyone they can. Others may not.

People also find that their need for information changes over time. Many of the patients we talked to said that in the beginning, general information about cancer and cancer treatment was the most helpful, or was all they could handle. Later, during their treatment, they found that they wanted more detailed information about their treatment and how it was going to affect them.

As a result, *Eating Hints for Cancer Patients* is organized in separate sections that relate to specific stages of cancer treatment. Each section can stand alone, so read as much or as little of the book as you need.

BEFORE TREATMENT BEGINS—This section briefly describes eating-related side effects that may occur with different types of cancer treatments. It also gives some tips to help you prepare physically and mentally for your treatment. See pages 4 to 7.

MANAGING EATING PROBLEMS DURING TREATMENT—This section provides more detailed information on specific eating-related side effects that people experience with their treatment. While many side effects are described, they may or may not happen to you. There is a wide variation in what patients experience. This section includes lots of suggestions for coping, as well as some recipes that patients and caregivers have found to be especially helpful. See pages 8 to 35.

AFTER TREATMENT ENDS —This section deals with the time period after your treatment ends. It gives you suggestions for getting back to a normal eating routine and provides tips for healthy eating. See pages 37 to 38.

***Eating Hints for Cancer Patients* also includes three other sections:**

SPECIAL NOTES FOR CAREGIVERS, which gives tips and suggestions for family members and other caregivers. See page 36.

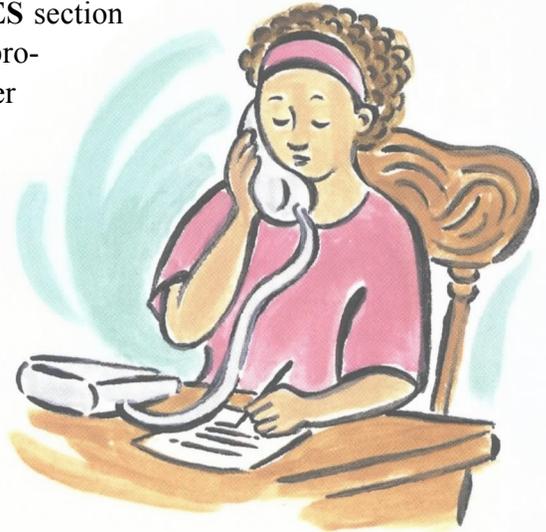
A GLOSSARY, which lists and explains words that relate to diet, nutrition, and other aspects of cancer care. Words appearing in **bold** throughout this booklet are defined in the Glossary. See pages 52 to 55.

RESOURCES, which includes information on other NCI publications about cancer, its treatment, and coping with the illness. We have also listed NCI's **Cancer Information Service (CIS)** at 1-800-4-CANCER. The CIS provides information about cancer, cancer treatment, research studies, and living with cancer to patients, their families, health professionals, and the public. In addition, this section includes information about nutrition publications published by NCI and the U.S. Departments of Agriculture and of Health and Human Services. See pages 56 to 58.

How To Use This Booklet

You may not want to read all of this booklet at one time. Flip through it and read the section that fits your situation now. Later, you can go back and read other sections as you need them. For example, many patients do not have eating-related side effects or these side effects may be mild. If you find that eating-related side effects are not an issue for you, then the “Before” and “After” sections of this booklet will be most useful. On the other hand, if you are bothered by one or more eating related side effects, the suggestions and recipes in “Managing Eating Problems During Treatment” may help you.

A registered dietitian *is your best source of information about your diet.* The information here will add to what the dietitian can tell you. Feel free to ask for help or advice when you need it. Writing down your questions in advance will help you make sure you get the information you need. Ask the dietitian to repeat or explain anything that is not clear. She or he can also explain anything in this book if you have a question and can give you more detailed information. Your doctor or nurse can also give you helpful advice and can refer you to a registered dietitian. If you cannot get a referral, call the American Dietetic Association’s (ADA) toll-free nutrition hotline. The information specialist you talk to can help you find a registered dietitian in your area. The **RESOURCES** section at the end of *Eating Hints* provides the telephone number and other contact information for the ADA.



Before Treatment Begins

When your cancer was first diagnosed, your doctor talked to you about a treatment plan. This may have involved **surgery, radiation therapy, chemotherapy, hormone therapy, and biologic (immunotherapy)**, or some combination of those treatments.

All of these methods of treating cancer kill **cells**. In the process of killing the cancer cells, some healthy cells are also damaged. That is what causes the side effects of cancer treatment. Side effects that can affect your ability to eat include:

- loss of appetite
- changes in weight (either losing or gaining weight)
- sore mouth or throat
- dry mouth
- dental and gum problems
- changes in sense of taste or smell
- nausea/vomiting
- diarrhea
- lactose intolerance
- constipation
- fatigue and/or depression

You may or may not have any of these side effects. Many factors determine whether you will have any and how severe they will be. These factors include the type of cancer you have, the part of your body being treated, the type and length of treatment, and the dose of treatment. The good news is that if you do have side effects they can often be well-controlled. Most side effects also go away after treatment ends. Your doctor or nurse can tell you more about your chances of having side effects and what they might be like.

Nutrition Recommendations Can Be Different for Cancer Patients

Recommendations about food and eating for cancer patients can be very different from the usual suggestions for healthful eating. This can be confusing for many patients because these new suggestions may seem to be the opposite of what they've always heard. **Nutrition** recommendations usually stress eating lots of fruits, vegetables, and whole grain breads and cereals; including a moderate amount of meat and dairy products; and cutting back on fat, sugar, alcohol, and salt. More information and tips on these recommendations are covered in the section **AFTER TREATMENT ENDS**.

Nutrition recommendations for cancer patients may focus on helping you eat more higher **calorie** foods that emphasize **protein**. Recommendations might include eating or drinking more milk, cream, cheese, and cooked eggs. Other suggestions might include increasing your use of sauces and gravies, or changing your cooking methods to include more butter, margarine, or oil. Sometimes, nutrition recommendations for cancer patients suggest that you eat less of certain high-**fiber** foods because these foods can aggravate problems such as diarrhea or a sore mouth.

Nutrition recommendations for cancer patients are different because they are designed to help build up your strength and help you withstand the effects of your cancer and its treatment. When you are healthy, eating enough food to get the **nutrients** you need is usually not a problem. During cancer treatment, however, this can become a challenge, especially if you have side effects or simply don't feel well.

Preparing Yourself for Cancer Treatment

Until your treatment actually starts, you won't know exactly what, if any, side effects you may have or how you'll feel. One way to prepare is to think of your treatment as a time for you to concentrate on yourself and on getting well. Here are some other ways to get ready:

Think Positively

- ◆ Many people have few or no eating-related side effects. Even if you do, they may be mild, and most go away after cancer treatment ends. Also, there are new drugs now that can work well to control side effects.
- ◆ Having a positive attitude, talking out your feelings, becoming well-informed about your cancer and treatment, and planning ways to cope can all help reduce worry and anxiety, make you feel more in control, and help you keep your appetite.
- ◆ Give food a chance. Even if you do have eating problems, you'll have days when eating is a pleasure.

Eat a Healthy Diet

- ◆ A healthy diet is vital for a person's body to work its best. This is even more important for cancer patients.
- ◆ If you've been eating a healthy diet, you'll go into treatment with reserves to help keep up your strength, prevent body **tissue** from breaking down, rebuild tissue, and maintain your defenses against **infection**.
- ◆ People who eat well are better able to cope with side effects. You may even be able to handle higher doses of certain treatments. For example, we know that some cancer treatments are actually much more effective if the patient is well-nourished and getting enough calories and protein in his or her diet.

- ◆ Don't be afraid to try new foods. Some things you may never have liked before may taste good to you during treatment.

Plan Ahead

- ◆ Stock the pantry and freezer with favorite foods so that you won't need to shop as often. Include foods you know you can eat even when you are sick.
- ◆ Keep foods handy that need little or no preparation, for example, pudding, peanut butter, tuna fish, cheese, and eggs.
- ◆ Do some cooking in advance and freeze in meal-sized portions.
- ◆ Talk to friends or family members about helping with shopping and cooking. Or, ask a friend or family member to manage that job for you.
- ◆ Talk to a registered dietitian about your concerns and what you might expect. She or he can give you ideas and help you plan meals. Ask for help in developing a grocery list with foods that might help with potential side effects, such as constipation or nausea. Ask about what has worked for other patients.



Managing Eating Problems During Treatment

All the methods of treating cancer — surgery, radiation therapy, chemotherapy, hormone therapy, and biological therapy (immunotherapy) — are very powerful. Although these treatments target the fast-growing cancer cells in your body, healthy cells can also be damaged. Healthy cells that normally grow and divide rapidly, such as those in the mouth, **digestive tract**, and hair, are often affected by cancer treatments. The damage to healthy cells is what produces the unpleasant side effects that cause eating problems. *Table 1* (pages 40-41) shows some of the effects that can occur as a result of cancer treatment.

Side effects of cancer treatment vary from patient to patient. The part of the body being treated, the type and length of treatment, and the dose of treatment determine whether side effects will occur.

The good news is that- not everyone has side effects during treatment, and most side effects go away when treatment ends. Side effects can also be well-controlled with new drugs. Talk to your doctor about possible side effects from your treatment and what can be done about them.

Some eating problems are caused by the treatment itself. Other times, patients may have trouble eating because they are upset, worried, or afraid. Losing your appetite and nausea are two normal responses to feeling nervous or fearful. Once you get into your treatment period and have a better sense of what to expect and how you will react, these anxiety-related eating problems should get better.

While you are in the hospital or undergoing treatment, talk to your doctor, nurse, or a registered dietitian. They can answer your questions and give you suggestions for specific meals, snacks, and foods, and for dealing with any eating problems you

may have. They can also help with dietary preferences that reflect various cultural and ethnic backgrounds. Feel free to talk to them if problems arise during your recovery as well. Ask them what has worked for other patients.

Remember, there aren't any hard and fast nutrition rules during cancer treatment. Some patients may continue to enjoy eating and have a normal appetite throughout most of their cancer treatment. Others may have days when they don't feel like eating at all; even the thought of food may make them feel sick. Here are some things to keep in mind:

- ◆ When you can eat, try to eat meals and snacks with sufficient protein and calories; they will help you keep up your strength, prevent body tissues from breaking down, and rebuild tissues that cancer treatment may harm.
- ◆ Many people find their appetite is better in the morning. Take advantage of this and eat more then. Consider having your main meal of the day early, and have liquid meal replacements later on if you don't feel so interested in eating (*see page 11 for more information on liquid meal replacements*).
- ◆ If you don't feel well and can eat only one or two things, stick with them until you are able to eat other foods. Try a liquid meal replacement for extra calories and protein.
- ◆ On those days when you can't eat at all, don't worry about it. Do what you can to make yourself feel better. Come back to eating as soon as you can, and let your doctor know if this problem doesn't get better within a couple of days.
- ◆ Try to drink plenty of **fluids**, especially on those days when you don't feel like eating. Water is essential to your body's proper functioning, so getting enough fluids will ensure that your body has the water it needs. For most adults, 6-8 cups of fluid a day are a good target. Try carrying a water bottle with you during the day. That may help you get into the habit of drinking plenty of fluids. **Tables 2 and 3** (pages 42 and 43) include many examples of fluids you can try.

Coping with Side Effects

This section offers practical hints for coping with treatment side effects that may affect your eating. These suggestions have helped other patients manage the same eating problems that you may have. Try all the ideas to find what works best for you. Share your needs and concerns with your family and friends, particularly those who prepare meals for you.

Let them know that you appreciate their support. Tell them about *Special Notes for Caregivers* (see page 36).

At the end of Eating Hints, on pages 51 and 59, you will find two items that may be especially useful as you go through treatment and use this booklet. The first, “Keeping Track of Side Effects,” is a chart that you copy and use to monitor how you feel as you go through treatment. Use the second, “Notes,” to jot down questions or concerns that you want to discuss with your health care team.

Loss of Appetite

Loss of appetite or poor appetite is one of the most common problems that occurs with cancer and its treatment. No one knows exactly what causes loss of appetite. It may be caused by the treatments or by the cancer itself. Emotions such as fear or depression can also take away a person’s appetite. Ask a nurse or social worker about ways to lessen these emotional difficulties. Sometimes it is the side effects of treatment such as nausea, vomiting, or changes in food’s taste or smell that make a person feel like not eating. If this is the cause, work with your doctor or nurse to get the side effects under better control.

For some people, loss of appetite happens for just a day or two; for others, it’s an ongoing concern. Whatever the reason, here are some suggestions that might help:

- ◆ Try liquid or powdered meal replacements, such as “instant breakfast,” during times when it is hard for you to eat food.
- ◆ Try frequent small meals throughout the day, rather than fewer big ones. It may be easier to eat more that way, and you won’t get so full.

Commercial Products to Improve Nutrition

If you cannot get enough calories and protein from your diet, commercial meal replacements such as drinks, “shakes,” and “instant breakfast” powders may help. Other products also can be added to any food or beverage. These supplements are high in protein and calories and have extra **vitamins** and **minerals**. They come in liquid, pudding, and powder forms. Most commercial meal replacements contain little or no **lactose**. However, it is important to check the label if you are sensitive to lactose. Your nurse or a registered dietitian can tell you which products are best for you and which ones are available in your area.

Most of these products need no refrigeration until you open them. That means you can carry them with you and have them whenever you feel hungry or thirsty. They are also good chilled as between-meal or bedtime snacks. You may want to take a can with you when you go for treatments or other times when you may have a long wait.

Many supermarkets and drugstores carry a variety of commercial liquid meal replacements. If you don't see these products on the shelf, ask the store manager if they can be ordered.

- ◆ Keep snacks within easy reach so you can have something whenever you feel like it. Cheese and crackers, muffins, ice cream, peanut butter, fruit, and pudding are good possibilities. Take a portable snack with you when you go out, such as peanut butter crackers or small boxes of raisins. You can find more snack ideas in **Table 4** on page 44.
- ◆ Even if you don't feel like eating solid foods, try to drink beverages during the day. Juice, soup, and other fluids like them can give you important calories and nutrients. Milk-based drinks also provide protein. **Tables 2 and 3** (pages 42 and 43) give lots of examples of fluids.

- ◆ If possible, try having something at bedtime. It won't affect your appetite for the next meal.
- ◆ Sometimes, changing the form of a food will make it more appetizing and help you eat better. For example, if eating whole, fresh fruit is a problem, try mixing fruit into a milkshake. Here's a sample:

Banana Milkshake

1 whole ripe banana, sliced
Vanilla extract (few drops)
1 cup milk

Place all ingredients into a blender.
Blend at high speed until smooth.



Yield: 1 serving

Serving size: Approximately 2 cups

If made with whole milk:

Calories per serving: 255 calories

Protein per serving: 9 grams

If made with 2% milk:

Calories per serving: 226 calories

Protein per serving: 9 grams

If made with skim milk:

Calories per serving: 190 calories

Protein per serving: 9 grams

- ◆ Try softer, cool, or frozen foods; such as yogurt, milkshakes, or popsicles.
- ◆ Take advantage of times when you do feel well, and have a larger meal then. Many people have a better appetite first thing in the morning, when they are well rested.
- ◆ During meals, sip only small amounts because drinking may make you feel full. If you want to have more than just a small amount to drink, have it 30-60 minutes before or after a meal.
- ◆ Make mealtimes as relaxed and pleasant as possible. Presenting food or meals in an attractive way may also help.
- ◆ If your doctor allows, have a small glass of wine or beer during a meal. It may help to stimulate your appetite.
- ◆ Regular exercise may help your appetite. Check with your doctor to see what options are open to you.

Weight Loss

Many cancer patients lose weight during their cancer treatment. This is partly due to the effects of the cancer itself on the body. Also, if you've lost your appetite and are eating less than usual because of your treatment or emotional worries, you may lose weight. Table 5: ***How to Increase Calories*** and Table 6: ***How to Increase Protein*** (pages 45 and 48) will give you some ideas for slowing weight loss or even gaining a few pounds. The tips under *Loss of Appetite* (page 10) may help, too.

On the next three pages are three simple recipes that show you how to increase the calories and protein of familiar foods:

Fortified Milk

1 quart whole milk

1 cup nonfat instant dry milk

Pour liquid milk into a deep bowl.

Add dry milk and beat slowly with beater until dry milk is dissolved (usually less than five minutes).

Refrigerate and serve cold.

Note: If it tastes too strong, start with 1/2 cup of dry milk powder and gradually work up to 1 cup.



Yield: 1 quart

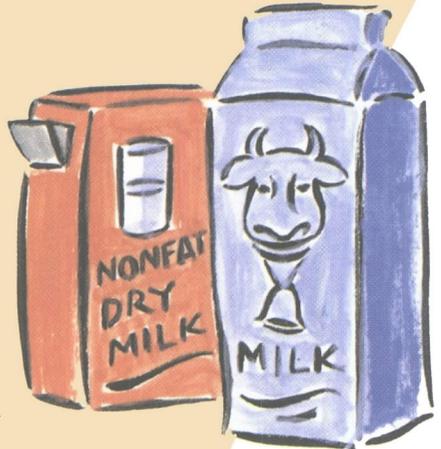
Serving size: 1 cup

Calories per serving: 211 calories

Protein per serving: 14 grams

Use fortified milk when making:

- ◆ macaroni and cheese
- ◆ puddings and custards
- ◆ cream sauces for vegetables
- ◆ mashed potatoes
- ◆ cocoa
- ◆ French toast or pancake batter
- ◆ soup





High-Protein Milkshake

1 cup fortified milk

2 tbsp butterscotch, chocolate, or your
favorite fruit syrup or sauce

1/2 cup ice cream

1/2 tsp vanilla extract

Put all ingredients in a blender.

Blend at low speed for 10 seconds.

Yield: 1 serving

Serving size: Approximately 1-1/2 cups

Calories per serving: 425 calories

Protein per serving: 17 grams

Instant Dry Milk as a Protein Powder

For extra protein in dishes, consider adding a little nonfat instant dry milk to scrambled eggs, soup, cereal, sauces, and gravies.

Peanut Butter Snack Spread

1 tbsp nonfat instant dry milk
1 tbsp honey
1 tsp water
5 tbsp smooth peanut butter
1 tsp vanilla extract

Combine dry milk, water, and vanilla, stirring to moisten.

Add honey and peanut butter, stirring slowly until liquid blends with peanut butter.

Spread on crackers.

Mixture also can be formed into balls, chilled, and eaten as candy.

Keeps well in refrigerator but is difficult to spread when cold.

Yield: 6 tbsp

Serving size: 3 tbsp

Calories per serving: 279 calories

Protein per serving: 11 grams



Weight Gain

Some patients find their weight does not change during treatment. They may even gain weight. This is particularly true for breast, prostate, and ovarian cancer patients taking certain medications or who are on hormone therapy or chemotherapy.

*It is important **not** to go on a diet right away if you notice weight gain.* Instead, tell your doctor so you can find out what may be causing this change. Sometimes, weight gain happens because certain anticancer drugs can cause your body to hold on to excess fluid. This condition is called **edema**. The weight comes from the extra water. If this is the case, your doctor may ask you to talk with a registered dietitian for guidelines on limiting the amount of salt you eat. This is important because salt causes your body to hold extra water. Your doctor may also want to prescribe a **diuretic**. This is a medication that causes your body to get rid of excess fluid.

Breast cancer patients with a primary diagnosis of cancer may be different. Over half of them may actually gain weight rather than lose during treatment. Because of this, many of the recommendations for breast cancer patients do emphasize a lower fat, reduced calorie diet similar to those provided to patients after cancer treatment has been completed (see page 37).

Weight gain may also be the result of increased appetite and eating extra food and calories. If this is the case and you want to stop gaining weight, here are some tips that can help. Talk to a registered dietitian for more guidance:

- ◆ Emphasize fruits, vegetables, and breads and cereals.
- ◆ Choose lean meats (lean beef or pork trimmed of fat, chicken without skin) and low-fat dairy products (skim or 1% milk, light yogurt).
- ◆ Cut back on added butter, mayonnaise, sweets, and other extras.
- ◆ Choose low-fat and low-calorie cooking methods (broiling, steaming).

- ◆ Avoid eating high-calorie snacks between meals.
- ◆ If you feel up to it, increase the amount of exercise you get.

Sore Mouth or Throat

Mouth sores, tender gums, and a sore throat or esophagus often result from radiation therapy, chemotherapy, or infection. If you have a sore mouth or gums, see your doctor to be sure the soreness is a treatment side effect and not an unrelated dental problem. The doctor may be able to give you medicine that will control mouth and throat pain. Your dentist also can give you tips for the care of your mouth.

Certain foods will irritate an already tender mouth and make chewing and swallowing difficult. By carefully choosing the foods you eat and by taking good care of your mouth, teeth, and gums, you can usually make eating easier. Here are some suggestions that may help:

- ◆ Try soft foods that are easy to chew and swallow, such as:
 - milkshakes
 - bananas, applesauce, and other soft fruits
 - peach, pear, and apricot nectars
 - watermelon
 - cottage cheese, yogurt
 - mashed potatoes, noodles
 - macaroni and cheese
 - custards, puddings, and gelatin
 - scrambled eggs
 - oatmeal or other cooked cereals
 - pureed or mashed vegetables, such as peas and carrots
 - pureed meats

Here's a simple blender recipe that's easy on a sore mouth:

Fruit and Cream

1 cup whole milk

1 cup vanilla ice cream or frozen yogurt

1 cup canned fruit (heavy syrup), including juice
(peaches, apricots, pears)

Almond or vanilla extract to taste

Blend ingredients and chill well before serving.

Yield: 2 servings

Serving size: 1-1/2 cups

If made with ice cream:

Calories per serving: 302 calories

Protein per serving: 7 grams

If made with frozen yogurt:

Calories per serving: 268 calories

Protein per serving: 9 grams



- ◆ Avoid foods or liquids that can irritate your mouth. These include:
 - oranges, grapefruits, lemons, or other citrus fruit or juice
 - tomato sauces or juice
 - spicy or salty foods
 - raw vegetables, granola, toast, crackers, or other rough, coarse, or dry foods
 - commercial mouthwashes that contain alcohol
- ◆ Cook foods until they are soft and tender.
- ◆ Cut foods into small pieces.
- ◆ Use a blender or food processor to puree your food.
- ◆ Mix food with butter, margarine, thin gravy, or sauce to make it easier to swallow.
- ◆ Use a straw to drink liquids.
- ◆ Use a smaller-than-usual spoon, such as a baby spoon.
- ◆ Try foods cold or at room temperature. Hot foods can irritate a tender mouth and throat.
- ◆ Try drinking warm bouillon or salty broth; it can soothe throat pain.
- ◆ Try sucking on ice chips.
- ◆ If swallowing is hard, tilting your head back or moving it forward may help.
- ◆ If your teeth and gums are sore, your dentist may be able to recommend a special product for cleaning your teeth.
- ◆ Rinse your mouth often with water to remove food and bacteria and to promote healing.
- ◆ Ask your doctor about anesthetic lozenges and sprays that can numb your mouth and throat long enough for you to eat meals.

Dry Mouth

Chemotherapy and radiation therapy in the head or neck area can reduce the flow of saliva and cause dry mouth. When this happens, foods are harder to chew and swallow. Dry mouth also can change the way foods taste. Some of the ideas for sore mouth and throat may help. The suggestions below also may help you deal with dry mouth.

- ◆ Have a sip of water every few minutes to help you swallow and talk more easily. Consider carrying a water bottle with you so you always have some handy.
- ◆ Try very sweet or tart foods and beverages, such as lemonade; these foods may help your mouth make more saliva. (*Do not try this if you also have a tender mouth or sore throat and the sweet or tart foods make it worse.*)
- ◆ Suck on hard candy or popsicles or chew gum. These can help make more saliva.
- ◆ Eat soft and pureed foods, which may be easier to swallow.
- ◆ Keep your lips moist with lip salves.
- ◆ Moisten food with sauces, gravies, and salad dressings to make it easier to swallow.
- ◆ If your dry mouth problem is severe, ask your doctor or dentist about products that coat, protect, and moisten your mouth and throat. These are sometimes called “artificial saliva.”



Dental and Gum Problems

Cancer and cancer treatment can cause tooth decay and other problems for your teeth and gums. For example, radiation to the mouth can affect your salivary glands, making your mouth dry and increasing your risk of cavities. Changes in eating habits also may add to the problem. Your doctor and dentist should work closely together to fix any problems with your teeth before you start treatment. If you eat often or eat a lot of sweets, you may need to brush your teeth more often. Brushing after each meal or snack is a good idea. Here are some other ideas for preventing dental problems:

- ◆ Be sure to let your doctor know about any dental problems you are having.
- ◆ Be sure to see your dentist regularly. Patients who are receiving treatment that affects the mouth — for example, radiation to the head and neck — may need to see the dentist more often than usual.
- ◆ Use a soft toothbrush. Ask your doctor, nurse, or dentist to suggest a special kind of toothbrush and/or toothpaste if your gums are very sensitive.
- ◆ Rinse your mouth with warm water when your gums and mouth are sore.
- ◆ If you are eating foods high in sugar or foods that stick to your teeth, be sure to brush or rinse your mouth afterward so that the sugar won't damage your teeth, or use sugar-free varieties. *(Sorbitol, a sugar substitute that is contained in many sugar-free foods, can cause diarrhea in many people. If diarrhea is a problem for you, check the labels of sugar-free foods before you buy them and limit your use of them.)*

Changed Sense of Taste or Smell

Your sense of taste or smell may change during your illness or treatment. Foods, especially meat or other high-protein foods, can begin to have a bitter or metallic taste. Many foods

will have less taste. Chemotherapy, radiation therapy, or the cancer itself may cause these problems. Dental problems also can change the way foods taste. For most people, changes in taste and smell go away when their treatment is finished.

There is no foolproof way to prevent changes to your sense of taste or smell because each person is affected differently by illness and treatments. However, the tips below should help if you have this problem. *(If you also have a sore mouth, sore gums, or a sore throat, talk to your doctor, nurse, or registered dietitian. They can suggest ways to help you without hurting the sore areas.)*

- ◆ Choose and prepare foods that look and smell good to you.
- ◆ If red meat, such as beef, tastes or smells strange, try chicken, turkey, eggs, dairy products, or mild-tasting fish instead.
- ◆ Help the flavor of meat, chicken, or fish by marinating it in sweet fruit juices, sweet wine, Italian dressing, or sweet-and-sour sauce.
- ◆ Try using small amounts of flavorful seasonings, such as basil, oregano, or rosemary.
- ◆ Try tart foods, such as oranges or lemonade, that may have more taste. A tart lemon custard might taste good and will also provide needed protein and calories. *(If you have a sore mouth or throat, tart or citrus foods might cause pain or discomfort.)*
- ◆ If smells bother you, try serving foods at room temperature, turning on a kitchen fan, covering foods when cooking, and cooking outdoors in good weather.
- ◆ Try using bacon, ham, or onion to add flavor to vegetables.
- ◆ Visit your dentist to rule out dental problems that may affect the taste or smell of food.
- ◆ Ask your dentist or doctor about special mouthwashes and good mouth care.

Nausea

Nausea, with or without vomiting, is a common side effect of surgery, chemotherapy, radiation therapy, and biological therapy. The disease itself, or other conditions unrelated to your cancer or treatment, may also cause nausea. Some people have nausea or vomiting right after treatment; others don't have it until two or three days after a treatment. Many people never experience nausea. For those who do, nausea often goes away once the treatment is completed. Also, there are now drugs that can effectively control this side effect. These medications, called **antiemetics**, are often given at the beginning of a chemotherapy session to prevent nausea.

Whatever the cause, nausea can keep you from getting enough food and needed nutrients. Here are some ideas that can help:

- ◆ Ask your doctor about antiemetics that might help you control nausea and vomiting.
- ◆ Try foods that are easy on your stomach, such as:
 - toast, crackers, and pretzels
 - yogurt
 - sherbet
 - angel food cake
 - cream of wheat, rice, or oatmeal
 - boiled potatoes, rice, or noodles
 - skinned chicken that is baked or broiled, not fried
 - canned peaches or other soft, bland fruits and vegetables
 - clear liquids
 - ice chips
 - carbonated drinks



- ◆ Avoid foods that:
 - are fatty, greasy, or fried
 - are very sweet, such as candy, cookies, or cake
 - are spicy or hot
 - have strong odors
- ◆ Eat small amounts, often and slowly. Eat before you get hungry, because hunger can make feelings of nausea stronger.
- ◆ If nausea makes certain foods unappealing, then eat more of the foods you find easier to handle.
- ◆ Avoid eating in a room that's stuffy, too warm, or has cooking odors that might disagree with you.
- ◆ Drink fewer liquids with meals. Drinking liquids can cause a full, bloated feeling.
- ◆ Slowly drink or sip liquids throughout the day. A straw may help.
- ◆ Have foods and drinks at room temperature or cooler; hot foods may add to nausea.
- ◆ Don't force yourself to eat favorite foods when you feel nauseated. This may cause a permanent dislike for those foods.
- ◆ Rest after meals, because activity may slow digestion. It's best to rest sitting up for about an hour after meals.
- ◆ If nausea is a problem in the morning, try eating dry toast or crackers before getting up.
- ◆ Wear loose-fitting clothes.
- ◆ If nausea occurs during radiation therapy or chemotherapy, avoid eating for 1 to 2 hours before treatment.
- ◆ Try to keep track of when your nausea occurs and what causes it (specific foods, events, surroundings). (see chart on page 51) If possible and if it helps, change your diet or schedule. Share the information with your doctor or nurse.

Vomiting

Vomiting may follow nausea and may be brought on by treatment, food odors, gas in the stomach or bowel, or motion. In some people, certain associations or surroundings, such as the hospital, may cause vomiting. As with nausea, some people have vomiting right after treatment, while others don't have it until a day or more after treatment.

If vomiting is severe or lasts for more than a day or two, contact your doctor. He or she may give you an **antiemetic** medication to control nausea and vomiting.

Very often, if you can control nausea, you can prevent vomiting. At times, though, you may not be able to prevent either. Relaxation exercises or meditation may help you. These usually involve deep rhythmic breathing and quiet concentration, and can be done almost anywhere. If vomiting does occur, try these suggestions to help prevent further episodes:

- ◆ Do not eat or drink anything until you have the vomiting under control.
- ◆ Once the vomiting is under control, try small amounts of clear liquids, such as water or bouillon. **Table 2** (page 42) gives you more examples of clear liquids. Begin with 1 teaspoonful every 10 minutes, gradually increasing the amount to 1 tablespoon every 20 minutes. Finally, try 2 tablespoons every 30 minutes.
- ◆ When you are able to keep down clear liquids, try a full-liquid diet or a **soft diet**. **Table 3** (page 43) gives examples of full-liquid foods. Continue taking small amounts as often as you can keep them down. If you feel okay, gradually work up to your regular diet. If you have a hard time digesting milk, you may want to try a soft diet instead of a full-liquid diet, because a full-liquid diet includes a lot of milk products. Ask a registered dietitian for information about a soft diet.

Diarrhea

Diarrhea may have several causes, including chemotherapy, radiation therapy to the abdomen, infection, food sensitivities, and emotional upset. Work with your doctor to identify the cause of your diarrhea so that it can be successfully treated.

During diarrhea, food passes quickly through the bowel before your body has a chance to absorb enough vitamins, minerals, and water. This may cause **dehydration**, which means that your body does not have enough water to work well. Long-term or-severe diarrhea may cause problems, so contact your doctor if the diarrhea is severe or lasts for more than a couple of days. Here are some ideas for coping with diarrhea:

- ◆ Drink plenty of fluids to replenish what you lose with the diarrhea. **Tables 2 and 3** (pages 42 and 43) give examples of fluids to try.
- ◆ Eat small amounts of food throughout the day instead of three large meals.
- ◆ Eat plenty of foods and liquids that contain **sodium** and **potassium**, two important minerals that help your body work properly. These minerals are often lost during diarrhea. Good high-sodium liquids include bouillon or fat-free broth. Foods high in potassium that don't cause diarrhea include bananas, peach and apricot nectar, and boiled or mashed potatoes. Sports drinks contain both sodium and potassium and have easily absorbable forms of carbohydrates.
- ◆ Try these foods:
 - yogurt, cottage cheese
 - rice, noodles, or potatoes
 - farina or cream of wheat
 - eggs (cooked until the whites are solid; not fried)
 - smooth peanut butter
 - white bread
 - canned, peeled fruits and well-cooked vegetables
 - skinned chicken or turkey, lean beef, or fish (broiled or baked, not fried)

- ◆ Avoid:
 - greasy, fatty, or fried foods if they make your diarrhea worse
 - raw vegetables and the skins, seeds, and stringy fibers of unpeeled fruits
 - high-fiber vegetables, such as broccoli, corn, dried beans, cabbage, peas, and cauliflower
- ◆ Avoid very hot or cold food or beverages. Drink liquids that are at room temperature.
- ◆ Limit foods and drinks that contain caffeine, such as coffee, some sodas, and chocolate.
- ◆ If you have a sudden, short-term attack of diarrhea, try having nothing but clear liquids for the next 12 to 14 hours. (see chart on page 51) This lets your bowel rest and replaces the important fluids lost during the diarrhea. Make sure your doctor or nurse knows about this problem.
- ◆ Be careful when using milk and milk products. The lactose they contain can make diarrhea worse. Most people, though, can handle small amounts (about 1-1/2 cups) of milk or milk products.



Special Diets for Special Needs

When you have special needs because of your cancer or treatment, your doctor or registered dietitian may prescribe a special diet. For example, a soft diet may be best if your mouth, throat, esophagus, or stomach is sore. Or, if your treatment makes it difficult for you to digest dairy products, you may need to follow a low-lactose diet. Other special diets include a clear-liquid diet, a full-liquid diet, and a fiber-restricted diet.

Some special diets are well balanced and can be followed for long periods of time. Others, however, should be followed for only a few days because they may not provide enough nutrients for the long term. If you think you need a special diet, talk with your doctor and a registered dietitian. Together, you can work out a plan. You also should work with your doctor and dietitian if you are already on a special diet for a disease such as diabetes, kidney, or heart disease.

Lactose Intolerance

Lactose intolerance means that your body can't digest or absorb the milk sugar called lactose. Milk, other milk-based dairy products (such as cheese and ice cream), and foods to which milk has been added (such as pudding) may contain lactose.

Lactose intolerance may occur after treatment with some antibiotics, with radiation to the stomach or with any treatment that affects the digestive tract. The part of your intestines that digests lactose may not work properly during treatment. For some people, the symptoms of lactose intolerance (gas, cramps, diarrhea) disappear a few weeks or months after the treatments end or when the intestine heals. For others, a permanent change in eating habits may be needed.

If you have this problem, your doctor may advise you to follow a diet that is low in foods that contain lactose. Talk to a registered dietitian to get advice and specific tips about how to

follow a low-lactose diet. Your supermarket should carry milk and other products that have been modified to reduce or eliminate the lactose. You can also make your own low-lactose or lactose free foods. Here's a simple recipe for a lactose-free pudding:

Lactose-Free Double Chocolate Pudding

- 2 squares baking chocolate (1 oz each)
- 1 cup nondairy creamer, soy formula or lactose-free milk
- 1 tbsp cornstarch
- 1/4 cup granulated sugar
- 1 tsp vanilla extract

Melt chocolate in small pan or on foil.

Measure cornstarch and sugar into saucepan.

Add part of the liquid and stir until cornstarch dissolves.

Add the remainder of the liquid.

Cook over medium heat until warm.

Stir in chocolate until mixture is thick and comes to a boil.

Remove from heat.

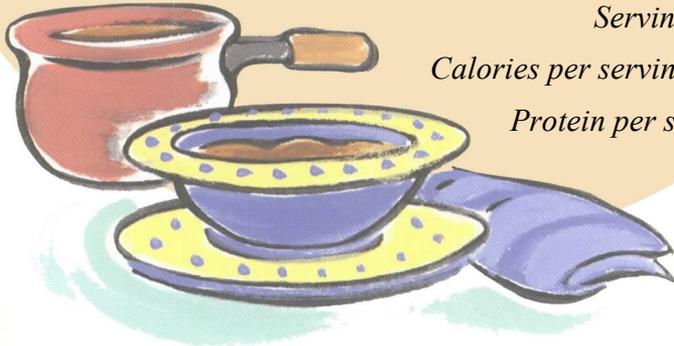
Blend in vanilla and cool.

Yield: 2 servings

Serving size: 3/4 cup

Calories per serving: 382 calories

Protein per serving: 1 gram



Constipation

Some anticancer drugs and other drugs, such as pain medications, may cause constipation. This problem also can occur if your diet lacks enough fluid or fiber, or if you've been in bed for a long time. Here are some suggestions for preventing and treating constipation:

- ◆ Drink plenty of liquids — at least eight 8-ounce glasses every day. This will help to keep your stools soft. Another way to think about fluids is to try to drink at least 1/2 oz. per pound of your body weight.
- ◆ Have a hot drink about one-half hour before your usual time for a bowel movement.
- ◆ Check with your doctor to see if you can increase the fiber in your diet (there are certain types of cancer for which a high-fiber diet is not recommended). If you can, try foods such as whole-grain breads and cereals, dried fruits, wheat bran, wheat germ; fresh fruits and vegetables; dried beans and peas. Eat the skin on potatoes. Make sure you also drink plenty of fluids to help the fiber work.

See the next page for an easy recipe that might help relieve constipation:

- ◆ Get some exercise every day. Talk to your doctors or a physical therapist about the amount and type of exercise that's right for you.

If these suggestions don't work, ask your doctor about medicine to ease constipation. *Be sure to check with your doctor before taking any laxatives or stool softeners.*

Apple/Prune Sauce

1/3 cup unprocessed bran

1/3 cup applesauce

1/3 cup mashed stewed prunes

Blend all ingredients and store in refrigerator.

Take 1-2 tablespoons of this mixture before bedtime, then drink 8 oz. of water.

Note: Make sure you drink the water, or else it will not work to relieve constipation.

Yield: 16 servings

Serving size: 1 tbsp

Calories per serving: 10 calories



Fatigue and Depression

All the methods of treating cancer treatment are powerful. Treatment may go on for weeks or months. It may even cause more illness or discomfort than the initial disease. Many patients say they feel exhausted and depressed, and unable to concentrate. Fatigue during cancer treatment can be related to a number of causes: not eating, inactivity, low blood counts, depression, poor sleep, and side effects of medicine. It is important for you to raise the issue with your health care team if you are having fatigue. Together, you can decide what is causing the problem, since many of the causes can be treated.

Fatigue and depression aren't eating problems in and of themselves, but they can affect your interest in food and your ability to shop and prepare healthy meals. Here are some suggestions that may help:

- ◆ Talk about your feelings and your fears. Being open about your emotions can make them seem more manageable. Consider talking with your nurse or social worker, who can help you find ways to lessen your worries and fears.
- ◆ Become familiar with your treatment, possible side effects, and ways of coping. Being knowledgeable and acting on that knowledge will help you feel more in control. Don't be afraid to talk with your doctor and ask questions.
- ◆ Make sure you get enough rest:
 - take several naps or rest breaks during the day, rather than one long rest
 - plan your day to include rest breaks
 - make rest time special with a good book in a comfortable chair or a favorite video with a friend
 - try easier or shorter versions of your usual activities; don't push yourself to do more than you can manage.
- ◆ Save your favorite foods for times that aren't associated with treatment sessions. That way, they won't be linked to an uncomfortable or distressing event.
- ◆ Take short walks or get regular exercise, if possible. Some people find this helps to lessen their fatigue and raise their spirits.

Preventing Food-Borne Illness

Cancer patients undergoing treatment can develop a weakened immune system because most anticancer drugs decrease the body's ability to make white blood cells, the cells that fight infection. That's why cancer patients should be especially careful to avoid infections and food-borne illnesses. Here are some tips to help you prevent food-borne illness:

- Wash all raw fruits and vegetables well. If it can't be well washed (as with raspberries), avoid it. Scrub rough surfaces, like the skin of melons, prior to cutting.
- Carefully wash your hands and food preparation surfaces (knives, cutting boards) before and after preparing food, especially after handling raw meat.
- Thaw meat in the refrigerator, not on the kitchen counter.
- Be sure to cook meat and eggs thoroughly.
- Avoid raw shellfish and use only pasteurized or processed ciders and juices and pasteurized milk and cheese.

The Food and Drug Administration has published a booklet that includes these and other tips for preventing food-borne illness. See the **RESOURCES** section for ordering information.

Extra Vitamins and Minerals — Will They Help?

Many cancer patients want to know whether vitamins, minerals, or other dietary supplements (such as phytochemicals) will help “build them up” or help fight their cancer. We know that patients who eat well during cancer treatment are better able to cope with their disease and any side

effects of treatment. However, there is no scientific evidence that dietary supplements or herbal remedies can cure cancer or stop it from coming back.

The NCI strongly urges you to depend on traditional, healthy foods for vitamins, minerals, and other nutrients. Talk to your doctor, nurse, registered dietitian, or a pharmacist before taking any vitamin or mineral supplements. Too much of some vitamins or minerals can be just as dangerous as too little. Large doses of some vitamins may even stop your cancer treatment from working the way it should. To avoid problems, don't take these products on your own. Follow your doctor's guidance.

What About Alternative Therapies?

You may hear or read about many different kinds of treatments people have tried to cure their disease. A therapy is called complementary when it is used in addition to conventional treatments; it is often called alternative when it is used instead of conventional treatment. A number of medical centers are evaluating the scientific aspects of complementary and alternative therapies and developing studies to test them. Many of these treatments have not been thoroughly studied, and we have no proof that they work or that they are safe. Other treatments have been studied, and we know they don't help or are harmful. It is important to talk with your doctor or nurse if you are considering trying any of these treatments, because some therapies may interfere with your standard treatment or may be harmful when used with conventional treatment. He or she can talk to you about any research that has been done and whether or not the treatment is safe or would interfere with your treatment. NCI strongly urges you to follow a treatment program prescribed by a doctor who uses accepted and proven methods or treatments. People who depend upon unconventional treatments alone may lose valuable treatment time and reduce their chances of controlling their cancer and getting well.

Special Notes for Caregivers

There is much that you can do to help your friend or loved one through the period of cancer treatment. Read over the tips and suggestions in “Managing Eating Problems During Cancer Treatment.” Many may be useful to you as you prepare food or meals for the patient.

In addition, here are some other things to remember that will help you cope:

- ◆ Be prepared for the patient’s tastes to change from day to day. Some days he or she won’t want favorite foods because they don’t taste good. Other times, he or she will be able to eat a dish that couldn’t be tolerated just the day before.
- ◆ Have food within easy reach at home. For example:
 - a snack-pack of applesauce or pudding and a spoon on the bedside table if the patient isn’t feeling well that day
 - a bag of cut-up carrots on the top shelf of the refrigerator
- ◆ Have meals and snacks ready so the patient can have something to eat when he or she is ready.
- ◆ Be prepared for times when the patient is able to eat only one or two foods for a few days in a row, until side effects diminish. Even if he or she can’t eat at all, still encourage plenty of fluids. Tables 2 and 3 (pages 42 and 43) contain a variety of examples of fluids, and the section on “Coping with Side Effects” has lots of ideas for getting enough fluids.
- ◆ Talk to the patient about needs and concerns, and about ideas that might work best. A willingness to be flexible and supportive no matter what will help the patient feel in control of the situation.
- ◆ Try not to push the patient into eating and drinking. Encourage and support without being overwhelming.

After Cancer Treatment Ends

Most eating-related side effects associated with radiation, chemotherapy, or other treatments go away after cancer treatment ends. If you have had side effects, you should gradually begin to feel better, and your interest in food and mealtimes will come back. Sometimes, though, side effects persist, especially weight loss. If this happens to you, talk to your doctor and work out a plan together for how to address the problem.

After cancer treatment ends and you're feeling better, you may want to think again about the traditional guidelines for healthy eating. Just as you wanted to go into treatment with all the reserves that such a diet could give you, you'll want to do the best for yourself at this important time. There's no current research that suggests that the foods you eat will prevent your cancer from recurring. But, we do know that eating right will help you regain your strength, rebuild tissue, and help you feel well. Here are the fundamentals:

- ◆ Focus on eating a variety of foods every day. No one food contains all the nutrients you need.
- ◆ Emphasize fruits and vegetables. Raw or cooked vegetables, fruits, and fruit juices provide the vitamins, minerals, and fiber you need.
- ◆ Emphasize breads and cereals, especially the whole grain varieties, such as whole wheat bread, oats, and brown rice. These foods are good sources of complex carbohydrates, vitamins and minerals, and fiber.
- ◆ Go easy on fat, salt, sugar, alcohol, and smoked or pickled foods. Choose low-fat milk products, and small portions (no more than 6-7 oz. a day) of lean meat and poultry without skin. Try lower-fat cooking methods, such as broiling, steaming, and poaching.

The U.S. Department of Agriculture and U.S. Department of Health and Human Services have published materials to help Americans learn how to choose a healthy diet. The RESOURCES section at the end of this booklet gives you information on how to get these materials. If you have any questions about guidelines for healthy eating, or whether such guidelines are right for you at this time, talk to a registered dietitian.

Some patients need to have treatments that last a long time. Others may have surgery to remove part of their stomach or intestines. These patients may have ongoing eating-related concerns. *If this is your situation, talk to your doctor and a registered dietitian. He or she can give you more information about the long-term issues that you will deal with and can help you develop an individual diet plan.*

Ways to Get Back Into Eating

Even if your treatment is over and you're feeling much better, you still may not feel completely back to your old self. Here are some ways to help you ease back to regular meals and mealtimes, without overdoing it:

- ◆ Make simple meals using familiar, easy-to-prepare recipes.
- ◆ Cook enough for two or three meals, then freeze the remainder for a later meal.
- ◆ Take advantage of the supermarket's salad bar and prepared foods to make cooking easier.
- ◆ Think about ways you used to make mealtime special and try them again.
- ◆ Don't be afraid to ask a friend or family member for help with cooking or shopping.



Table 1. How Cancer Treatments Can Affect Eating

Cancer Treatment	How It Can Affect Eating
Surgery	Increases the need for good nutrition. May slow digestion. May lessen the ability of the mouth, throat, and stomach to work properly. Adequate nutrition helps wound-healing and recovery.
Radiation Therapy	As it damages cancer cells, it also may affect healthy cells and healthy parts of the body.
Chemotherapy	As it destroys cancer cells, it also may affect the digestive system and the desire or ability to eat.
Biological Therapy (Immunotherapy)	As it stimulates your immune system to fight cancer cells, it can affect the desire or ability to eat.
Hormonal Therapy	Some types can increase appetite and change how the body handles fluids.

What Sometimes Happens: Side Effects

Before surgery, a high-protein, high-calorie diet may be prescribed if a patient is underweight or weak. After surgery, some patients may not be able to eat normally at first. They may receive nutrients through a needle in their vein (such as in **total parenteral nutrition**), or through a tube in their nose or stomach.

Treatment of head, neck, chest, or breast may cause:

- Dry mouth
- Sore mouth
- Sore throat
- Difficulty swallowing (**dysphagia**)
- Change in taste of food
- Dental problems
- Increased phlegm

Treatment of stomach or pelvis may cause:

- Nausea and vomiting
- Diarrhea
- Cramps, bloating
- Nausea and vomiting
- Loss of appetite
- Diarrhea
- Constipation
- Sore mouth or throat
- Weight gain or loss
- Change in taste of food
- Nausea and vomiting
- Diarrhea
- Sore mouth
- Severe weight loss
- Dry mouth
- Change in taste of food
- Muscle aches, fatigue, fever
- Changes in appetite
- Fluid retention

Table 2. Examples of Clear Liquids

Bouillon
Clear, fat-free broth
Clear carbonated beverages
Consomme
Cranberry/grape juice
Fruit-flavored drinks
Fruit ices without fruit pieces
Fruit ices without milk
Fruit punch
Honey
Jelly
Plain gelatin dessert
Popsicles
Sports drinks
Strained citrus juice
Strained lemonade/limeade
Strained vegetable broth
Tea
Water

Table 3. Examples of Full-Liquid Foods

All fruit juices and nectars
Bouillon, broth
Butter/cream/oil/margarine
Carbonated beverages
Cheese soup
Coffee/Tea
Fresh or frozen plain yogurt
Fruit drinks
Fruit punch
Honey/jelly/syrup
Ice milk
Liquid meal replacements
Milk, all types
Milkshakes
Pasteurized eggnog
Plain cornstarch pudding
Plain gelatin desserts
Potatoes pureed in soup
Refined/strained cooked cereal
Sherbet
Small amounts of strained meat in broth or gelatin
Smooth ice cream
Soft or baked custard
Strained lemonade/limeade
Strained or blenderized soup
Thin fruit purees
Tomato juice
Tomato puree for cream soup
Vegetable juice
Water

Table 4. Quick & Easy Snacks

Applesauce
Bread, muffins, and crackers
Buttered popcorn
Cakes and cookies made with whole grains, fruits, nuts,
wheat germ, or granola
Cereal
Cheese, hard or semisoft
Cheesecake
Chocolate milk
Crackers
Cream soups
Dips made with cheese, beans, or sour cream
Fruit (fresh, canned, dried)
Gelatin salads and desserts
Granola
Hard-boiled and deviled eggs
Ice cream frozen yogurt, popsicles
Juices
Milkshakes, “instant breakfast” drinks
Nuts
Peanut butter
Pita bread and hummus
Pizza
Puddings and custards
Sandwiches
Vegetables (raw or cooked)
Whole or 2% milk
Yogurt

Table 5. How to Increase Calories

Butter and Margarine	<ul style="list-style-type: none">• Add to soups, mashed and baked potatoes, hot cereals, grits, rice, noodles, and cooked vegetables.• Stir into cream soups, sauces, and gravies.• Combine with herbs and seasonings, and spread on cooked meats, hamburgers, and fish and egg dishes.• Use melted butter or margarine as a dip for seafoods and raw vegetables, such as shrimp, scallops, crab, and lobster.
Whipped Cream	<ul style="list-style-type: none">• Use sweetened on hot chocolate, desserts, gelatin, puddings, fruits, pancakes, and waffles.• Fold unsweetened into mashed potatoes or vegetable purees.
Milk and Cream	<ul style="list-style-type: none">• Use in cream soups, sauces, egg dishes, batters, puddings, and custards.• Put on hot or cold cereal.• Mix with noodles, pasta, rice, and mashed potatoes.• Pour on chicken and fish while baking.• Use as a binder in hamburgers, meat-loaf, and croquettes.• Use whole milk instead of low-fat.• Use cream instead of milk in recipes.• Make hot chocolate with cream and add marshmallows.
Cheese	<ul style="list-style-type: none">• Melt on top of casseroles, potatoes, and vegetables.• Add to omelets.• Add to sandwiches.

(continued on next page)

Table 5. How to Increase Calories *(continued)*

Cream Cheese	<ul style="list-style-type: none">• Spread on breads, muffins, fruit slices, and crackers.• Add to vegetables.• Roll into balls and coat with chopped nuts, wheat germ, or granola.
Sour Cream	<ul style="list-style-type: none">• Add to cream soups, baked potatoes, macaroni and cheese, vegetables, sauces, salad dressings, stews, baked meat, and fish.• Use as a topping for cakes, fruit, gelatin desserts, breads, and muffins.• Use as a dip for fresh fruits and vegetables.• For a good dessert, scoop it on fresh fruit, add brown sugar, and refrigerate until cold before eating.
Salad Dressings and Mayonnaise	<ul style="list-style-type: none">• Use with sandwiches.• Combine with meat, fish, and egg or vegetable salads.• Use as a binder in croquettes.• Use in sauces and gelatin dishes.
Honey, Jam, and Sugar	<ul style="list-style-type: none">• Add to bread, cereal, milk drinks, and fruit and yogurt desserts.• Use as a glaze for meats, such as chicken.
Granola	<ul style="list-style-type: none">• Use in cookie, muffin, and bread batters.• Sprinkle on vegetables, yogurt, ice cream, pudding, custard, and fruit.• Layer with fruits and bake.• Mix with dry fruits and nuts for a snack.• Substitute for bread or rice in pudding recipes.

(continued on next page)

Dried Fruits
(raisins, prunes,
apricots, dates, figs)

- Try cooking dried fruits; serve for breakfast or as a dessert or snack.
 - Add to muffins, cookies, breads, cakes, rice and grain dishes, cereals, puddings, and stuffings.
 - Bake in pies and turnovers,
 - Combine with cooked vegetables, such as carrots, sweet potatoes, yams, and acorn and butternut squash.
 - Combine with nuts or granola for snacks.
-

Eggs

- Add chopped, hard-cooked eggs to salads and dressings, vegetables, casseroles, and creamed meats.
 - Make a rich custard with eggs, milk, and sugar.
 - Add extra hard-cooked yolks to deviled-egg filling and sandwich spread.
 - Beat eggs into mashed potatoes, vegetable purees, and sauces. (Be sure to keep cooking these dishes after adding the eggs because raw eggs may contain harmful bacteria.)
 - Add extra eggs or egg whites to custards, puddings, quiches, scrambled eggs, omelets, and to pancake and French toast batter before cooking.
-

Food Preparation

- Bread meat and vegetables.
- If tolerated, saute and fry foods when possible, because these methods add more calories than do baking or broiling.
- Add sauces or gravies.

Table 6. How to Increase Protein

Hard or Semisoft Cheese	<ul style="list-style-type: none">• Melt on sandwiches, bread, muffins, tortillas, hamburgers, hot dogs, other meats or fish, vegetables, eggs, desserts, stewed fruit, or pies.• Grate and add to soups, sauces, casseroles, vegetable dishes, mashed potatoes, rice, noodles, or meatloaf.
Cottage Cheese/ Ricotta Cheese	<ul style="list-style-type: none">• Mix with or use to stuff fruits and vegetables.• Add to casseroles, spaghetti, noodles, and egg dishes, such as omelets, scrambled eggs, and souffles.• Use in gelatin, pudding-type desserts, cheesecake, and pancake batter.• Use to stuff crepes and pasta shells or manicotti.
Milk	<ul style="list-style-type: none">• Use milk instead of water in beverages and in cooking when possible.• Use in preparing hot cereal, soups, cocoa, and pudding.• Add cream sauces to vegetables and other dishes.
Nonfat Instant Dry Milk	<ul style="list-style-type: none">• Add to regular milk and milk drinks, such as pasteurized eggnog and milkshakes.• Use in casseroles, meatloaf, breads, muffins, sauces, cream soups, mashed potatoes, puddings and custards, and milk-based desserts.
Commercial Products	<ul style="list-style-type: none">• See the section on “Commercial Products to Improve Nutrition” on page 10.• Use “instant breakfast” powder in milk drinks and desserts.• Mix with ice cream, milk, and fruit or flavorings for a high-protein milkshake.

(continued on next page)

Ice Cream, Yogurt, and Frozen Yogurt

- Add to carbonated beverages, such as ginger ale or cola.
- Add to milk drinks, such as milkshakes.
- Add to cereal, fruit, gelatin desserts, and pies; blend or whip with soft or cooked fruits.
- Sandwich ice cream or frozen yogurt between cake slices, cookies, or graham crackers.
- Make breakfast drinks with fruit and bananas.

Eggs

- Add chopped, hard-cooked eggs to salads and dressings, vegetables, casseroles, and creamed meats.
- Add extra eggs or egg whites to quiches and to pancake and French toast batter.
- Add extra egg whites to scrambled eggs and omelets.
- Make a rich custard with eggs, high-protein milk, and sugar.
- Add extra hard-cooked yolks to deviled-egg filling and sandwich spreads.
- Avoid raw eggs, which may contain harmful bacteria, because your treatment may make you susceptible to infection. Make sure all eggs you eat are well cooked or baked; avoid eggs that are undercooked.

Nuts, Seeds, and Wheat Germ

- Add to casseroles, breads, muffins, pancakes, cookies, and waffles.
- Sprinkle on fruit, cereal, ice cream, yogurt, vegetables, salads, and toast as a crunchy topping; use in place of bread crumbs.
- Blend with parsley or spinach, herbs, and cream for a noodle, pasta, or vegetable sauce.
- Roll banana in chopped nuts.

(continued on next page)

Table 6. How to Increase Protein *(continued)*

Peanut Butter

- Spread on sandwiches, toast, muffins, crackers, waffles, pancakes, and fruit slices.
 - Use as a dip for raw vegetables, such as carrots, cauliflower, and celery.
 - Blend with milk drinks and beverages.
 - Swirl through soft ice cream and yogurt.
-

Meat and Fish

- Add chopped, cooked meat or fish to vegetables, salads, casseroles, soups, sauces, and biscuit dough.
 - Use in omelets, souffles, quiches, sandwich fillings, and chicken and turkey stuffings.
 - Wrap in pie crust or biscuit dough as turnovers.
 - Add to stuffed baked potatoes.
-

Beans/Legumes

- Cook and use peas, legumes, beans, and tofu in soups or add to casseroles, pastas, and grain dishes that also contain cheese or meat. Mash cooked beans with cheese and milk.

Keeping Track of Side Effects

Here's a form to help you keep track of eating-related side effects you may experience while you are undergoing cancer treatment. Feel free to copy this form and keep your own record. You can also share it with the health professional who is keeping track of side effects with you during this time.

Your Name: _____ Week of: _____

Write the type and date of your last treatments(s):

Type of Treatment: _____ Date(s): _____

Your Weight: _____ lbs. (measure once a week)

Below you will find a list of some eating-related side effects that cancer patients may experience. Check the box next to any side effect listed below that you experience in the week you have listed above. Next to each one you have checked, write a number from 1 to 3 indicating how severe you think each side effect was for you, where:

1 = mild; 2 = moderate; and 3 = severe.

Side Effect	M	T	W	Th	F	S	Sun
Appetite	<input type="checkbox"/> __						
Sore/Dry Mouth	<input type="checkbox"/> __						
Nausea	<input type="checkbox"/> __						
Vomiting	<input type="checkbox"/> __						
Constipation	<input type="checkbox"/> __						
Diarrhea	<input type="checkbox"/> __						
Fatigue	<input type="checkbox"/> __						
Other: _____	<input type="checkbox"/> __						

Other Questions or Concerns (Use this space to write down questions or concerns you may want to talk about with your health care provider.) _____

Glossary

Adjuvant treatment: anticancer drugs or hormones given after surgery and/or radiation to help prevent the cancer from coming back.

Anorexia: Loss of appetite leading to severe weight loss,

Antiemetics: Drugs used to control nausea and vomiting.

Biological therapy (immunotherapy): Treatment to stimulate or restore the ability of the immune system to fight infection and disease. This treatment uses products from the body's natural defense system to destroy cancer cells.

Calorie: A measurement of the energy your body gets from food. Your body needs calories as “fuel” to perform all of its functions, such as breathing, circulating the blood, and physical activity. When you are sick, your body may need extra calories to fight fever or other problems.

Cells: The smallest units of tissues that make up any living thing. All cells have very specialized structures and functions and are able to reproduce.

Chemotherapy: The use of drugs to treat cancer.

Dehydration: When the body loses too much water to work well. Severe diarrhea or vomiting can cause dehydration.

Diet: The things you eat and drink, both liquids and solids.

Digestive tract: The parts of the body involved with eating, digesting, and excreting food. It includes the mouth, esophagus, stomach, and intestines.

Diuretics: Drugs that help the body get rid of water and salt.

Dysphagia: Difficulty swallowing.

Edema: The buildup of excess fluid within the tissues, such as in ankles, legs, arms, abdomen.

Fiber: The part of plant foods that the body cannot digest. It helps to move food waste out of the body more quickly. Fiber is found in fruits, vegetables, dry beans and peas, nuts and seeds, and breads and cereals. Fiber is not found in animal foods (meat, milk, eggs).

Fluids: Things to drink; liquids.

Hormone therapy: The use of drugs that block hormones in the treatment of breast, prostate, and other cancers. This therapy is used to prevent recurrence.

Immunotherapy: See “biological therapy.”

Infection: When germs enter the body and produce disease, the disease is called an infection. Infections can occur in any part of the body. They cause a fever and other problems, depending on the site of the infection. When the body’s natural defense system is strong, it can often fight the entering germs and prevent infection. Cancer treatment can weaken the natural defense system, but healthy eating can help make it stronger.

Lactose: Lactose is a sugar found in milk and milk products.

Lactose intolerance: The inability to easily digest lactose. This may be inherited, or may occur after some types of surgery. Surgery-related lactose intolerance may go away over time. Many stores carry special milk products that do not contain lactose.

Minerals: Nutrients needed by the body in small amounts to help it function properly and stay strong. Iron, calcium, potassium, and sodium are minerals.

Nutrient: Chemical compounds (water, protein, fat, carbohydrate, vitamins, minerals) that make up foods. These compounds are used in different ways by the body, i.e., to grow, function and stay alive.

Nutrition: A three-part process that gives the body the nutrients it needs. First, you eat or drink food. Second, the body breaks the food down into nutrients. Third, the nutrients travel through the bloodstream to different parts of the body where they are used as “fuel” and for many other purposes. To give your body proper nutrition, you have to eat and drink enough of the foods that contain key nutrients.

Phytochemicals: A class of helpful chemical substances found in plants. Many of these chemicals are thought to reduce your risk of cancer.

Potassium: A mineral the body needs for fluid balance and other essential functions.

Protein: One of the three nutrients that supply calories to the body (the other two are fats and carbohydrates). The protein we eat becomes a part of our muscle, bones, skin, and blood.

Radiation therapy: Treatment with high-energy x-rays to treat diseases such as cancer. External radiation therapy is the use of a machine to aim high-energy x-rays at the cancer. Internal radiation therapy is the placement of radioactive material inside the body as close as possible to the cancer.

Registered dietitian: A health care professional with extensive scientific background in food, nutrition, biochemistry, and physiology. This knowledge is applied to promoting health, preventing disease, and providing counseling and education.

Sodium: A mineral required by the body to keep body fluids in balance. Sodium is found in table salt. Too much sodium can cause you to retain water.

Soft diet: A diet consisting of bland, lower fat foods that you soften by cooking, mashing, pureeing or blending.

Surgery: An operation.

Tissue: Groups or layers of cells that perform a specific function.

Total parenteral nutrition: When a person receives needed nutrients through a needle in a vein.

Vitamins: Key nutrients, such as vitamins A, C, and E, that the body needs in small amounts to grow and stay strong.

Resources

Information about cancer is available from many sources, including the ones listed below. For additional information, you may wish to check the local library, bookstores, or support groups in your community. The health, science, or local events section of your local newspaper may list cancer support or information resources. The Internet can be a source of information about cancer and cancer treatment. NCI's Cancer Information Service can link you to reliable Internet sources of cancer information.

Organizations

National Cancer Institute

Cancer Information Service (CIS)

The CIS, a national information and education network, is a free public service of the NCI, the Nation's primary agency for cancer research. The CIS meets the information needs of patients, the public, and health professionals. Specially trained staff provide the latest scientific information in understandable language. CIS staff answer questions in English and Spanish and distribute NCI materials. To reach the CIS, call the toll-free phone number: 1-800-4-CANCER (1-800-422-6237); TTY: 1-800-332-8615.

NCI Fax and Electronic Services

CancerFax®: For NCI information by fax, dial 301-402-5874 from the telephone on a fax machine and listen to recorded instructions.

You can also use electronic mail (email) or the Internet to acquire information from PDQ, a database listing NCI-sponsored clinical trials, or other information by computer.

CancerNet™ Mail Service: To obtain a contents list, send an email to cancernet@icicc.nci.nih.gov with the word "help" in the body of the message.

CancerNet™ by Internet: To access CancerNet over the Internet, use the World Wide Web (<http://cancernet.nci.nih.gov>).

American Dietetic Association (ADA)

The ADA is a professional society of registered dietitians and other professionals working in food- and nutrition-related fields. For a referral to a registered dietitian in your area and to listen to recorded food and nutrition messages, call the ADA's consumer nutrition hotline at 1-800-366-1655. For individualized answers to your food and nutrition questions, call 1-900-CALL-AN-RD (1-900-225-5267). The cost of the call is \$1.95 for the first minute and \$.95 for each additional minute. Or, visit the ADA's home page on the World Wide Web at <http://www.eatright.org>.

Print Materials

- ◆ NCI has produced many booklets for cancer patients and their families. You may find some of them helpful during your treatment. You can get any of them by calling the CIS at 1-800-4-CANCER (1-800-422-6237). Here are just a few:
 - *Chemotherapy and You: A Guide to Self-Help During Treatment*
 - *Helping Yourself During Chemotherapy: 4 Steps for Patients*
 - *Radiation and You: A Guide to Self-Help During Treatment*
 - *Taking Time: Support for People with Cancer and the People Who Care for Them*
 - *Facing Forward: A Guide for Cancer Patients*
 - ◆ The National Cancer Institute and the U.S. Department of Agriculture and U.S. Department of Health and Human Services have published several materials on healthy eating. You may find them helpful after your treatment is over. They include:
 - *Action Guide for Healthy Eating*
National Cancer Institute
- To get a copy, call 1-800-4-CANCER (1-800-422-6237).

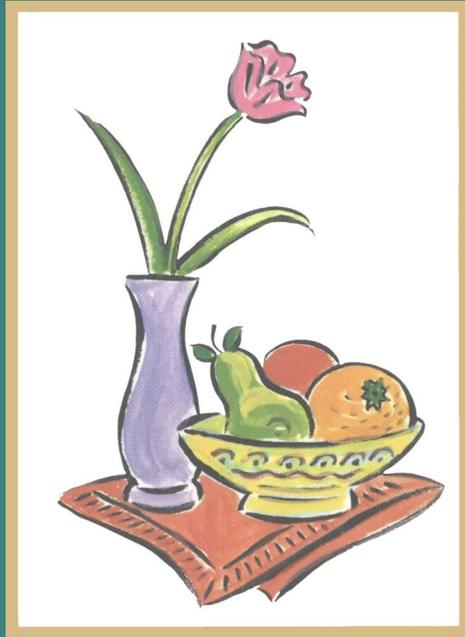
- *Nutrition and Your Health: Dietary Guidelines for Americans*
U.S. Department of Agriculture and U.S. Department of Health and Human Services
- *The Food Guide Pyramid*
U.S. Department of Agriculture

To get a copy of either publication or other USDA nutrition publications, write to:

U.S. Department of Agriculture
Human Nutrition Information Service
6505 Belcrest Road
Hyattsville, MD 20782

- ◆ The Food and Drug Administration (FDA) has published a booklet called “The Unwelcome Dinner Guest: Preventing Food-Borne Illness,” which contains useful information and tips on symptoms of food-borne illness, safe food storage, safe cooking and storing temperatures, safe food handling, and other topics related to preventing food-borne illness. Cancer patients and others with weakened immune systems need to be careful about food-borne illness, so this booklet may be especially helpful. To get up to 10 free copies, call the FDA Office of Consumer Affairs at 1-800-532-4440, or write to:

Food and Drug Administration
Office of Consumer Affairs
5600 Fishers Lane
Room 1675, HFE 88
Rockville, MD 20857



NATIONAL[®]
CANCER
INSTITUTE

NIH Publication No. 99-2079

Revised July 1997

Printed August 1999

RHYTHMIC WALKING

Developed by Maryl L. Winningham RN, MSN, APRN, PhD

Introduction

Decreased physical activity, which may be the result of illness or of treatment, can lead to tiredness and lack of energy. Scientists have found that even healthy athletes forced to spend extended periods in bed or sitting in chairs develop feelings of anxiety, depression, weakness, fatigue, and nausea. Regular moderate exercise can prevent these feelings, and help a person feel energetic and stay active.

People undergoing cancer therapy or recovering from cancer may have fatigue and weakness. The purpose of this booklet is to help such people develop a safe exercise program using a method we have called **Rhythmic Walking**.

This program is designed for individuals who are out of bed for at least half the day and who can carry on most of their normal daily activities. *Check with your doctor before starting the program.*

Everyone – however old or young, fat or thin, active or not – can benefit from exercise. Many people with cancer who engage in moderate exercise, such as **Rhythmic Walking**, say they feel better and more energetic. They also report fewer side effects from their treatments.

This booklet is your guide to a safe, beneficial exercise program. Please read it completely before beginning **Rhythmic Walking**. We suggest that you share the information with a friend or family member who can encourage you, and possibly walk with you.

We have provided spaces for you to personalize the information in this booklet. In addition, an Exercise Diary form is included for you to record your progress. Please share this record, as well as any concerns you may have, with your nurse or physician.

Most of all, this booklet is to invite you to enjoy the benefits of physical exercise.

What is Rhythmic Walking?

Rhythmic Walking consists of walking briskly, arms swinging, so your whole body is involved in the rhythm of your movement,

It is *not* race walking. It is very important you do not push yourself too hard.

It is *not* gently ambling, stopping to smell the flowers!

It *is* moving your arms and legs briskly in a rhythmic way so your heart rate is increased.

It *is* a regular program to benefit every system of your body.

Rhythmic Walking is a great way to exercise – *it can also be fun!*

What are the benefits of exercise?

Unnecessary bed rest or sitting can be hazardous to your health! Your body works on the use it or lose it principle. Sitting or lying down more than is necessary results in increased fatigue and weakness. It is important to stay as physically active as you can. Even during cancer therapy, it is often possible to continue exercise. This helps hearts and lungs get the necessary oxygen, and prevents muscles from becoming weak and lazy.

Here is a list of some of the benefits associated with exercise:

- Lower blood pressure
- Improvement in the heart's pumping ability
- More energetic feeling, less fatigue
- Increased endurance
- Stronger tendons, ligaments, joints, and bones
- Easing the pain or stiffness of arthritic joints
- A more positive attitude, less strain and tension
- Better sleeping patterns
- Improved appetite.

What is the right kind of exercise?

A good exercise plan starts slowly, allowing your body time to adjust. It is important that you do something to exercise the whole body on a regular basis. *Regular* means every day, or at least every other day. The right kind of exercise never makes you feel sore, stiff, or exhausted.

What is the wrong kind of exercise?

Even more dangerous than doing no exercise at all is being a Saturday Athlete. This is the person who exercises only occasionally - perhaps just on Saturdays - and who does too much, too fast. *If you experience soreness, stiffness, exhaustion, or feel out of breath as a result of your exercise, you are overdoing it.*

How do you start a Rhythmic Walking program?

We repeat: *First check with your physician.*

Before starting a program, it is important to know if there are precautions you need to take. This is especially important if you have high blood pressure, diabetes, or heart disease. People with these conditions can exercise, but they must follow certain guidelines to do it safely. It is also important to know what precautions to take if you have joint or bone problems, sprains or fractures, arthritis, or if you have cancer in your bones.

As a reminder, write the precautions mentioned by your physician in this space:

What do you need for Rhythmic Walking?

Rhythmic Walking is inexpensive. It requires no special equipment or uniforms. Wear comfortable clothes in which you can move freely. You *must* have, however, the right kind of shoes. A watch with a second hand to measure your heart rate is also important.

Every person who exercises outside the home should carry identification (see identification card at back of book). It is wise to carry change for a telephone call and money for a taxi. Some people like to carry a small water bottle such as a plastic soda bottle. To carry these items, a small backpack or one of the pouches designed for athletes that straps around your waist is useful. It leaves your hands free to swing during **Rhythmic Walking**.

Shoes: The right kind of shoes can be found at most shoe stores. However, it may be worth going to a store that specializes in athletic shoes. Flat shoes, such as basketball or tennis shoes, or hard soled shoes are not suitable for walking. Running or jogging shoes, or the shoes specially designed for walking are good. The wrong shoes can cause painful damage, such as tendonitis.



Use this checklist to find a good shoe for **Rhythmic Walking**, or to determine if shoes you already have are appropriate.

- Select shoes designed for walking, jogging, or running.
- Look for a shock-absorbent cushioning midsole.
- Look for skid-proof soles.
- Check for a comfortable feel on your foot. The shoes must feel right the first time you wear them. You should not need to break them in.
- Shop for shoes in the afternoon because your feet tend to be larger than in the morning.
- Try on both shoes. because your feet may be different sizes.
- Examine the shoes carefully for rough spots that could cause soreness or blisters.

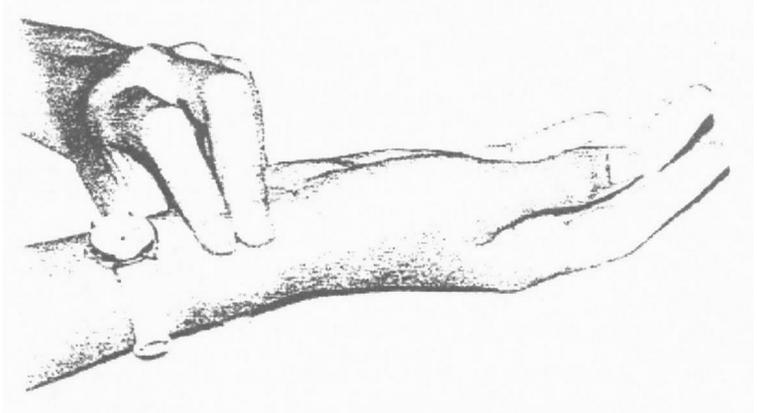
Clothes: In cold weather, layer your clothing with cotton or polypropylene next to your skin, then wool, and possibly a windbreaker and windproof pants. In summer, shorts or cotton pants and T-shirts are fine. If you are walking outside, and particularly if you walk in the early morning or late evening, *wear clothing that makes you visible* to traffic. Wear something that is white, brightly colored, or is reflective.

If it is wet, slippery, hot, or if you feel unsafe waking in your neighborhood, enclosed shopping malls can be great places for **Rhythmic Walking**. Some malls open early, before the shopping crowds arrive, especially for people who want to walk.

How hard should you exercise?

Your heart rate is the best indicator of how hard your body is working. As you work harder, your heart rate increases. As you slow down, your heart rate decreases. To estimate your heart rate, you can take your pulse.

If you have trouble finding a pulse, ask your nurse for help. For beginners, it is often easier to take another person's pulse. The best place for pulse-taking is at the wrist. When the heart beats, it produces a pulse. Taking your pulse is a good way to measure your heart rate.



First, check your resting pulse rate. To do this, sit quietly for a few minutes or count your pulse rate before getting up in the morning. Count your pulse for 60 seconds. For example, if your pulse count is 72 in 60 seconds; your heart rate is 72 beats per minute. Fill in your own resting heart rate:

_____beats/minute.



When you are **Rhythmic Walking**, your heart rate will increase. It is difficult to feel your pulse when actually walking. Stop briefly to measure your pulse. To get a quick estimate of your exercise heart rate, turn your watch so you can see it, count your pulse for 6 seconds and multiply by 10 (that is, add a zero). For example, if you count 13 beats in 6 seconds, $13 \times 10 = 130$, Your estimated exercise heart rate is 130 beats per minute.

To experience the benefits of exercise, you need to work hard enough to get your heart rate up to a certain point called the **Training Heart Rate** and keep it there. This chart shows the Training Heart Rate for people of different ages. (See next page).

HEART RATE CHART

Age in years	Suggested Training Hear: Rate*	6 Sec Count
Less than 20	140 to 150	14 or 15
20 - 30	130 to 140	13 or 14
30 - 40	120 to 130	12 or 13
40 - 50	110 to 120	11 or 12
50 - 60	100 to 110	10 or 11
60 and up	90 to 100	9 or 10

*Note: This chart is designed For individuals who have been cleared for exercise by their physicians and who are not on any medications that affect heart rate. Certain drugs, including some prescribed for heart or blood pressure problems or for migraine headaches, can affect heart rate. The above chart would not be valid for individuals taking those medications.

Record here what your Training Heart Rate should be according to the chart.

_____ beats per minute

Walk around the room slowly. Stop and estimate your exercise pulse rate as described above. Walk faster and estimate again. Now walk rapidly and swing your arms vigorously. Check your pulse again. Record your pulse in beats per minute under the following conditions:

_____ walking slowly

_____ walking faster

_____ brisk walking, swinging arms vigorously

If your heart rate is higher than the number listed in the chart, slow down. If it is slower, speed up a little and try swinging your arms more.

If you work too hard and get your heart rate up too high, you will fatigue rapidly and be unable to keep up your activity. On days when you are tired or stressed, you may notice that your resting heart rate is higher than usual. Take it easier on those days.

How long should you exercise?

It is important to start exercising slowly and build up gradually. If you have been very ill or have not been exercising on a regular basis, start with a 5 - or 10 - minute **Rhythmic Walk** and add 2 minutes each week. For example:

- First week - 5 minutes per day
- Second week - 7 minutes per day
- Third week - 9 minutes per day

If you are able to build up endurance without problems, work up to 45 minutes daily or every other day. More than 60 minutes of **Rhythmic Walking** daily is not necessary.

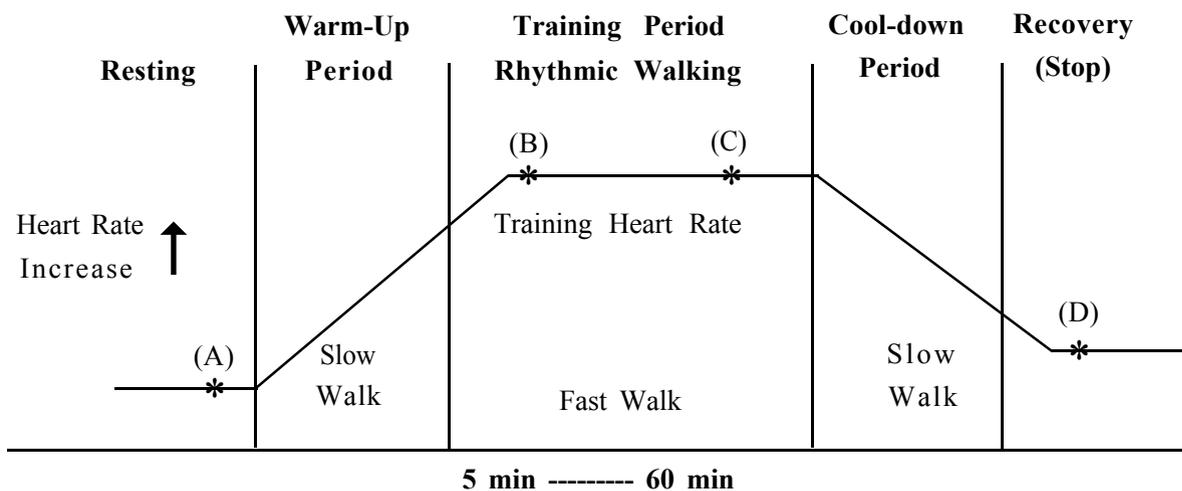
A good work-out consists of three phases: warm-up, training period, and cool-down. The warm-up is necessary to prepare the body for exercise. Warm up by walking slowly.

Begin **Rhythmic Walking**. This is your training period. Work up to your target heart rate and walk steadily for your set period of time.

Walk slowly to cool off. The cool-down is necessary to help your body recover and to prevent soreness or stiffness.

If you are exercising correctly, you should never feel exhausted after the cool-down. If you do, slow down and take it easier next time. If you feel fatigued for hours after exercise or if you feel sore and stiff, you have done too much or exercised incorrectly.

Here is a chart showing what happens to your heart rate during the three phases of exercise. Stars (*) marked from A to D show when you should check your pulse.



Record your heart rate at the starred times:

(A) _____ (B) _____ (C) _____ (D) _____
Before Starting 5 min into Walk 5 min before slowing 10 min after stopping

Special tips and precautions

The leading cause of winter injuries to walkers is slipping on ice.

In hot weather, the chief danger is dehydration, or lack of fluid. Do not wait until you are thirsty. Drink fluid at every opportunity. Children and older people, especially those who have been ill, are most at risk in hot weather. The lazy, tired feeling that commonly accompanies hot, humid weather is often a sign of dehydration. Other signs of dehydration include:

- Dry, cracked lips and mouth
- Thirst (older adults may not feel thirsty)
- Decreased urine output
- Headache

Never push yourself until you are tired. *Do not walk so far that you are too tired to walk back.* It is a good idea to have someone go with you, especially after a period of serious illness or treatments. Also, do not walk alone in isolated areas.

If you have to be hospitalized for a time, ask a nurse to tell you the distance round the hallways. In many hospitals, this has been measured so you can tell how far you are Walking. It is not uncommon to see someone with an IV pole charging up and down hospital hallways. Be sure to check with your nurse or your physician when you first come in for tests or treatment. In some cases, it may be important that you NOT exercise. Certain drugs and tests require that you rest. If this is the case, ask your nurse or physician when he or she thinks you may safely resume your activity.

Special points to consider when you are receiving treatment

If you are undergoing chemotherapy, radiation therapy, or immunotherapy, keep in mind the following precautions:

- Do not exercise for several hours before having laboratory tests such as blood tests.
- Take it easy the day of your chemotherapy. Walk your normal pace and do not increase your heart rate as you would for **Rhythmic Walking**.
- Do not **Rhythmic Walk** if you have an infection or a fever.
- If you have been laid up with surgery or an infection, wait until the day you feel better - then wait one more day before starting to exercise again. Begin slowly.
- Avoid crowded public places such as health spas, gyms, or busy malls when your white count is down.
- Take good care of your feet and avoid blisters, which can become infected.
- If you develop bleeding, or persistent soreness or pain, tell your nurse or physician about it.
- Do not **Rhythmic Walk** if your platelet count drops below 50,000.

Here is an example of an Exercise Diary:

Take your heart rate at starred (*) times.

Date/ Time	(A) *	(B) *	(C) *	(D) *	Time/ Distance	Location/Conditions/Comments
8/23 6:00p.m.	78	120	130	90	40 min. 2 miles	Neighborhood - warm evening Felt good
8/24	92	—	—	—	—	blood count down - chemo day felt nauseated - no exercise
8/25 6:00p.m.	82	130	130	92	25 min. 1 mile	Took it easy - walked in neighborhood still felt tired from yesterday
8/26	80	130	130	92	1 mile	Shopping mall - Very hot day Felt stronger today

Photocopy the Exercise Diary (page 9) of this booklet and keep a record of how your own **Rhythmic Walking** program is going. The last column is for notes where you walked, what kind of conditions you experienced, how you felt, any comments about your treatment or state of health that may have affected your progress that day (such as drug dose, blood counts, and any other comments you feel are important). Keep your Exercise Diary in a notebook or file so that you can keep track of your progress and can share it with your nurse or physician. Carefully kept records can be useful for the clinicians planning your care.

Planning for your

PEACE

of

MIND



**Senator Alma
Wheeler Smith**

18th District
P.O. Box 30036
Lansing, MI 48909-7536
1-800-344-2562



Dear Friend,

Some decisions we would rather put off indefinitely. Making a will and designating what kind of medical care we want if we become unable to speak for ourselves are two of those decisions.

Anything that forces us to think about our own mortality makes most of us uncomfortable. Nevertheless, it is wise to make such decisions before they become necessary. By taking the initiative, our loved ones do not have to guess what our desires would have been. If tragedy strikes, preplanning can eliminate much of the confusion and trauma.

This booklet has been prepared with the hope it will make this preplanning a little easier. It provides basic information about our Michigan statutory wills and durable powers of attorney for health care. It also includes forms for implementing some of these decisions.

Finally, it includes a form for recording personal and legal information, as well as notifying your loved ones where important documents are located.

The information in this booklet should be updated at least annually, and kept where it is easily accessible.

Planning for your
PEACE OF MIND

Table of Contents

PERSONAL RECORDS 3

MEDICAL AND PRESCRIPTION RECORDS 15

MICHIGAN STATUTORY WILL 19

ADVANCE DIRECTIVES FOR HEALTH CARE 33

ORGAN DONATION 45

PERSONAL RECORDS

PERSONAL RECORDS OF

A RESIDENT OF THE STATE OF MICHIGAN

Your name _____

Address _____

Telephone no. _____

Date completed _____

Where Important Papers May Be Found

YOUR WILL

Do you have a will? _____

My will is kept _____

Personal representative _____

Address _____

Lawyer _____

Address _____

Date of will _____

The date is important. If your will is OLD, you may also wish to review it in the light of changed circumstances such as: marriage; divorce; change in assets; birth or adoption of children since the will was signed; death of any beneficiaries; changes in state or federal law; change of residence; unavailability of witnesses; or death, age, or failing powers of the person named as personal representative.

REMEMBER: If you do not have a will, your estate will be distributed as provided by state law. Its formula for distribution may not be the same as you would want. Your wishes and your family's special needs can best be satisfied if you make a will.

REAL ESTATE

Do you own real estate? _____ Home _____ Other _____

For each piece of real estate you own:

Real Estate #1

Is title to the property in your name alone or in joint names? _____

Is there a mortgage on the property? _____

Who holds the mortgage? _____

Address _____

Real Estate #1 *(Continued)*

The deed, a copy of the mortgage, survey, title insurance policy, and closing documents are kept _____

Real estate tax receipts are kept _____

Do you have fire insurance? _____

Do you have liability insurance? _____

Policies are kept _____

For advice as to keeping or selling the property, consult. _____

Address _____

Real Estate #2

Is title to the property in your name alone or in joint names? _____

Is there a mortgage on the property? _____

Who holds the mortgage? _____

Address _____

The deed, a copy of the mortgage, survey, title insurance policy, and closing documents are kept _____

Real estate tax receipts are kept _____

Do you have fire insurance? _____

Do you have liability insurance? _____

Policies are kept _____

For advice as to keeping or selling the property, consult _____

Address _____

Real Estate #3

Is title to the property in your name alone or in joint names? _____

Is there a mortgage on, the property? _____

Who holds the mortgage? _____

Address _____

The deed, a copy of the mortgage, survey, title insurance policy, and closing documents are kept _____

Real estate tax receipts are kept _____

Do you have fire insurance? _____

Do you have liability insurance? _____

Policies are kept _____

For advice as to keeping or selling the property, consult _____

Address _____

Additional notes

LIFE INSURANCE

Do, you have life insurance? _____

Company _____ Policy No. _____

Is the life insurance in trust? _____

Trustee _____

Address _____

Who is the beneficiary? _____

Policies are kept _____

Any unpaid loans secured by policies? _____

Who is the lender? _____

Insurance advisor _____

Address _____

MILITARY, FRATERNAL OR COMPANY INSURANCE

Do you have military, fraternal, or company insurance? _____

Company _____ Policy No. _____

Who is the beneficiary? _____

Is the life insurance in trust? _____

Address _____

Policies are kept _____

Any unpaid loans secured by policies? _____

Who is the lender? _____

Insurance advisor _____

Address _____

OTHER PERSONAL INSURANCE — Do you have:

Health and accident insurance? _____

Company _____

Policy No. _____

Hospitalization insurance? _____

Company _____

Policy No. _____

Insurance for medical and surgical expenses? _____

Company _____

Policy No. _____

Policies are kept _____

SOCIAL SECURITY

Social Security No. _____

Card is kept _____

Employment record is kept _____

PENSION AND RETIREMENT INFORMATION

Do you have a pension or other retirement program? _____

No. _____ Is there a survivor benefit? _____

Contact _____

Address _____

FAMILY RECORDS

Born in _____

Date _____

Married in _____

Date _____

Where are birth certificates (or other proof of dates of birth) of members of family, marriage certificates, any naturalization papers, or discharge papers and other data as to military service?

BANK RECORDS

Do you have a checking account(s)? _____

Where is/are your checking account(s)? _____

Bank _____

Address _____

Account No. _____

Is it in your name alone or in joint names? _____

Do you have a savings account(s)? _____

Where is/are your savings account(s)? _____

Bank _____

Address _____

Account No. _____

Is it in your name alone or in joint names? _____

Do you have a certificate of deposit? _____

Where is your certificate of deposit? _____

Bank _____

Address _____

Account No. _____

Is it in your name alone or joint names? _____

Bank books and canceled checks are kept _____

Do you have an IRA? _____

IRA account location _____

Do you have a safe deposit box? _____

Bank _____

Address _____

Is it jointly held? _____ Key is kept _____

U.S. SAVINGS BONDS

Do you have any U.S. saving bonds? _____

Where are they? _____

In whose names are they registered? _____

I have designated a co-owner or a beneficiary, whose name is listed below:

Yes _____ Name _____ No _____

Do you have a list of bonds, by serial number and denomination? _____

Location of this list _____

OTHER BONDS AND CORPORATE STOCKS

Do you own any otherbonds or any preferred or common stocks?

Sole owner _____ Joint owner _____

Were are they? _____

Broker _____

Address _____

List and records of purchases are kept _____

OTHER PERSONAL PROPERTY

In whose name is your motor vehicle(s) titled under? _____

Vehicle title and insurance policy are kept _____

Are household furnishings insured? _____

Household furnishings insurance policy is kept _____

Policies, inventory, and bills of sale are kept _____

CEMETERY PLOT

Do you own a cemetery plot? _____

Where? _____

Deed is kept _____

IF SELF-EMPLOYED

Business name _____

Address _____

Copies of business agreements, other documents are kept _____

For advice as to handling or disposition of the business, consult _____

Address _____

IF NOT SELF-EMPLOYED

Employer _____

Address _____

Telephone _____

In emergency, call _____

OTHER MATTERS

Personal creditors or debtors, if any _____

Copies of notes, loan agreements, and receipts are kept _____

Income tax records and supporting data are kept _____

Credit card records are kept _____

Tax advisor _____

Address _____

Names, ages and relationship of those who would inherit property under your will (heirs, devisees, and beneficiaries):

Name	Age	Relationship	Address

Are any of the above under legal disability or otherwise represented by personal representatives?

Name	Legal Disability	Represented by: Name and address:

MEDICAL AND PRESCRIPTION RECORDS

MEDICAL INFORMATION

My allergies and drug sensitivities: _____

My blood type: _____

Medical conditions I have: _____

DOCTORS WHO ARE TREATING ME

Name _____ Specialty _____ Phone _____

Name _____ Specialty _____ Phone _____

Name _____ Specialty _____ Phone _____

Hospital _____

Name _____ Emergency Phone Number _____

Pharmacy _____

Name _____ Phone _____

Dentist _____

Name _____ Phone _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

Prescription Information

Name of drug _____

Date prescribed _____

Doctor's name _____

Prescribed for what? _____

Color/shape/strength _____

Directions/cautions _____

**MICHIGAN
STATUTORY WILL**

QUESTIONS AND ANSWERS

Michigan Statutory Will

1. What happens if I die without a will?

With certain exceptions, your possessions are distributed according to state law.

2. What can I accomplish by making out a will?

You can choose who is to receive your property; select someone to serve as personal representative (formerly known as executor); and appoint a guardian for your children under age 18.

3. Does having a will avoid probate procedures after my death?

No. The issue of whether probate procedures must be followed is not solely dependent on whether or not you have a will.

4. What property is not subject to probate procedures?

Property such as: money held in a joint bank account; real estate, if your spouse's name or a joint tenant's name is on the deed; and life insurance benefits, if a person living at the time of your death was named as a beneficiary in the policy.

5. If property is specified in my will, am I prevented from giving it away or selling it during my life?

No. Your will has absolutely no effect until you die. If you sell or give away property mentioned in the will, that provision of the will is simply ignored.

6. Are there different types of wills?

Yes. Each type is equally valid if done precisely in accordance with the law. It is recommended that you see a lawyer if you wish to draft a will and not use the statutory will form provided in this booklet.

7. What are some of the things I can accomplish through a statutory will?

- (a) You can leave up to two cash gifts of any amount to people or charities..
- (b) You Can write a list of personal and household items and name. the person or entity to receive each item.
- (c) You can ensure that the rest of your property goes to your spouse. If he or she dies before you, the property is to be distributed equally among your children.
- (d) You can select a personal representative to administer your property.
- (e) You can appoint a guardian and conservator in case you and your spouse both die before your children reach age 18.

8. Are there any reasons for me NOT to use the statutory will form provided in this brochure?

There may be. If, for instance, you have substantial wealth and need tax planning for your estate, you should consult a lawyer who handles estate planning and probate and have a will prepared. Consultation with a lawyer is strongly recommended if you want to establish a trust fund for your children's education, if you have assets outside the state of Michigan, or if you have a significant interest in a business or partnership.

9. I have a wife and two young children. Might a statutory will be appropriate for my purposes?

Perhaps. A statutory will might be appropriate if you do not have extensive assets and, therefore, do not need tax planning. In a statutory will, you can appoint a guardian for your children and a conservator for your children's assets.

10. I would like to leave my favorite niece an antique brooch. Can I do this with a statutory will?

Yes. A statutory will allows you to leave gifts of personal items by making a list of the items and the person you want to receive each item.

11. I am a widow with no children. Could a statutory will be appropriate for me?

If you do not have substantial assets and you do not object to the limited options for disposing of your property, you may want to use the statutory will form.

12. I own a house, a condominium, and much stock. Should I use a statutory will?

Perhaps not. A statutory will is not designed to reduce federal or state taxes on your estate. If you have very substantial assets, you may wish to check with a lawyer to see if tax planning is recommended.

13. I am married for the second time and my husband and I each have children from our first marriages. Would a statutory will be appropriate for my purposes?

Probably not. The statutory will provides that your estate goes to your husband if he survives: you. For that reason, the statutory will may not give you an adequate way to provide for the children from your first marriage. Speaking with a lawyer is likely a good idea for a person involved in a second marriage.

14. I have rather complicated business interests, which I wish to pass on through my will. Would a statutory will be appropriate for my purposes?

No. A statutory will does not provide for any specific business planning.

15. What should I do if a statutory will doesn't meet my needs?

Contact a lawyer with knowledge of estate planning. He or she can draft a will to meet your specific needs.

16. How can I find a good lawyer?

There is no sure-fire way. Here are some suggestions:

- (a) If you have dealt with a lawyer in the past and were satisfied, go back to that person. A lawyer who does not handle estate planning may recommend someone, who does.
- (b) Ask friends, neighbors or relatives.
- (c) Ask a person you respect, such as a religious leader, or call an organization such as a consumer group or a civic organization.
- (d) Call the county or state bar referral service, which will provide you with the names of lawyers.
- (e) Consult the business section of your telephone directory or newspaper classified section.

Don't be intimidated. Don't be afraid to "shop around" for someone you are comfortable with and whose services you can afford.

17. How do I use the statutory will form?

First, thoroughly read the entire form. Read the notice at the beginning and the definitions at the end. After you are sure you understand all of the will's provisions, carefully follow directions and fill in the blanks.

18. Can a statutory will be a joint will?

No. A husband and wife cannot both use a single statutory will. If one spouse chooses to use a statutory will, the other spouse is free to complete a separate statutory will or to choose a different type of will.

19. May I use a statutory will form and yet leave no cash gifts? (Article 2.1)

Yes. You may leave no cash gifts, one cash gift or two cash gifts. If you do leave a cash gift, it is particularly important that you give a complete address of the person or charity to receive the money.

20. How do I go about preparing a list of personal items? (Article 2.2)

List the possessions such as jewelry, books, automobiles, furniture, and other personal and household items on a separate piece of paper. On the list you should name who is to receive each item—a family member, friend or neighbor. The list can be as short or long as you choose. Make sure you describe each item sufficiently to avoid confusion. For each person who is to get an item, include his or her full name and address. The list must be in your handwriting or signed by you at the end. It is a very good idea to include the date. You may make the list before you complete the statutory will form, at the same time, or afterward. You can change the list as often as you wish. It is a good idea to staple or firmly attach the newest list to your will.

21. What is the purpose of Article 2.3?

This provision sets out the distribution of your property (other than cash gifts and the list of items) if your spouse, children, grandchildren and great-grandchildren all die before you. You have a choice: you may leave all the property to your other blood relatives who survive you, or leave one half to those relatives and one half to your spouse's blood relatives. Make your choice by signing your name under the appropriate paragraph.

22. Need I complete Article 3.2 if all of my children are over 18?

No. You may skip Article 3.2 relating to guardians and conservators.

23. How do I decide whether to have my personal representative serve with or without bond? (Article 3.3)

Most people these days request that the personal representative serve without bond. If you are careful to choose a person you trust to be personal representative, you may wish that no money be spent for a bond.

24. Who may be a witness to my will?

Any adult who will not receive any possessions or money under your will may be a witness. This is important. A person who may receive money or property under your will cannot be a witness to your will. You need not tell witnesses about the contents of your will.

25. After the will is completed, where should I keep it?

One option is to file it in probate court; such filings cost very little. Wherever you keep the will, it is a good idea to attach the list of personal items to the will. You may want to give a copy of the will to the person you have selected as personal representative.

26. Can I make changes to my statutory will?

Yes. Since a will has absolutely no effect until you die, you can change the will during your life. But do not write on the will. You can either complete a new statutory will, or have a codicil (an amendment to the old will) or an entirely new will drafted by a lawyer. If you signs new will, destroy copies of the old one. You can change the list of personal property items at any time. It is probably best to write a whole new list if you decide to make changes.

27. If move from Michigan would my statutory will still be valid?

Probably yes. It would be a good idea to check with a lawyer who practices law in the state of your new residence.

28. Does my statutory will need to be notarized?

No. ■

MICHIGAN STATUTORY WILL

NOTICE

1. Any person age 18 or older and of sound mind may sign a will.
2. There are several kinds of wills. If you choose to complete this form, you will have a Michigan statutory will. If this will does not meet your wishes in any way, you should talk with a lawyer before choosing a Michigan statutory will.
3. Warning! It is strongly recommended that you do not add or cross out any words on this form except for filling in the blanks because all or part of this will may not be valid if you do so.
4. This will has no effect. on jointly-held assets, on retirement plan benefits, or on life insurance on your life if you have named a beneficiary who survives you.
5. This will is not designed to reduce inheritance or estate taxes.
6. This will treats adopted children and children born outside of wedlock who would inherit, if their parent died without a will the same way as children born or conceived during marriage.
7. You should keep this will in your safe deposit box or other safe place. By paying a small fee, you may file the will in your county's 'probate court for safekeeping. You should tell your family where the will is kept.
8. You may make and sign a new will at any time. If you marry or divorce after you sign this will, you should make and sign a new will.

INSTRUCTIONS

1. To have a Michigan statutory will, you must complete the blanks on the will form. You may do this yourself, or direct someone to do it for you. You must either sign the will or direct someone else to sign it in your name and in your presence.
2. Read the entire Michigan statutory will carefully before you begin filling in the blanks. If there is anything you do not understand, you should ask a lawyer to explain it to you.

Michigan Statutory Will of

(Print or type your full name)

Article 1. Declarations

This is my will and I revoke any prior wills and codicils. I live in

_____ County, Michigan.

My spouse is _____
(Insert spouse's name or write "None")

My children now living are: (Insert names or write "None")

Article 2. Disposition of My Assets

2.1 CASH GIFTS TO PERSONS OR CHARITIES. (Optional)

I can leave no more than two (2) cash gifts. I make the following cash gifts to the persons or charities in the amounts stated here. Any inheritance tax due shall be paid from the balance of my estate and not from these gifts.

Full name and address of person or charity to receive cash gift.
(Name only one (1) person or charity here)

(Please print) _____
(Insert name)

of _____
(Insert address)

AMOUNT OF GIFT *(In figures)*: \$ _____

AMOUNT OF GIFT *(In words)*: _____ dollars

(Your signature)

Full name and address of person or charity to receive cash gift.

(Name only one (1) person or charity here)

(Please print) _____
(Insert name)

of _____
(Insert address)

AMOUNT OF GIFT *(In figures)*: \$ _____

AMOUNT OF GIFT *(In words)*: _____ dollars

(Your signature)

2.2 PERSONAL AND HOUSEHOLD ITEMS.

I may leave a separate list or statement, either in my handwriting or signed by me at the end, regarding gifts of specific books, jewelry, clothing, automobiles, furniture, and other personal and household items.

I give my spouse all my books, jewelry, clothing, automobiles, furniture and other personal and household items not included on any such separate list or statement. If I am not married at the time I sign this will, or if my spouse dies before me, my personal representative shall distribute those items, as equally as possible, among my children who survive me. If no children survive me, these items shall be distributed as set forth in paragraph 2.3.

Any inheritance tax due shall be paid from the balance of my estate and not from these gifts.

2.3 ALL OTHER ASSETS.

I give everything else I own to my spouse. If I am not married at the time I sign this will, or if my spouse dies before me, I give these assets to my children and the descendants of any deceased child. If no spouse, children, or descendants of children survive me, I choose one of the following distribution clauses by signing my name on the line after that clause. If I sign on both lines, or if I fail to sign on either line, or if I am not now married, these assets will go under distribution clause (b).

Distribution Clause, If No Spouse, Children, Or Descendants of Children Survive Me. *(Select only one)*

(a) One-half to be distributed to my heirs as if I did not have a will, and one-half to be distributed to my spouse’s heirs as if my spouse had died just after me without a will.

(Your signature)

(b) All to be distributed to my heirs as if I did not have a will.

(Your signature)

Article 3. Nominations of Personal, Representative, Guardian, and Conservator

Personal representatives, guardians, and conservators have a great deal of responsibility. The role of a personal representative is to collect your assets, pay debts and taxes from those assets, and distribute the remaining assets as directed in the will. A guardian is a person who will look after the physical well-being of a child. A conservator is a person who will manage a child's assets and make payments from those assets for the child's benefit. Select them carefully. Also, before you select them, ask them whether they are willing and able to serve.

3.1 PERSONAL REPRESENTATIVE. *(Name at least one)*

I nominate _____
(Insert name of person or eligible financial institution)

of _____
(Insert address)

to serve as personal representative.

If my first choice does not serve, I nominate _____
(Insert name of person or eligible financial institution)

_____ *(Insert address)*

to serve as personal representative.

3.2 GUARDIAN AND CONSERVATOR.

Your spouse may die before you. Therefore, if you have a child under age 18, name a person as guardian of the child, and a person or eligible financial institution as conservator of the child's assets. The guardian and the conservator may, but need not be, the same person.

If a guardian or conservator is needed for any child of mine, I nominate

_____ *(Insert name of person)*

of _____ as guardian
(Insert address)

and _____ of
(Insert name of person or eligible financial institution)

_____ *(Insert address)*

conservator.

If my first choice cannot serve, I nominate

(Insert name of person)

of _____ as guardian
(Insert address)

and _____ of
(Insert name of person or eligible financial institution)

(Insert address) as

conservator.

3.3 BOND.

A bond is a form of insurance in case your personal representative or a conservator performs improperly and jeopardizes your assets. A bond is not required. You may choose whether you wish to require your personal representative and any conservator to serve with or without a bond. Bond premiums would be paid out of your assets. (Select only one)

(a) My personal representative and any conservator I have named shall serve with bond.

(Your signature)

(b) My personal representative and any conservator I have named shall serve without bond.

(Your signature)

3.4 DEFINITIONS AND ADDITIONAL CLAUSES.

Definitions and additional clauses found at the end of this form are part of this will.

I sign my name to this Michigan statutory will on _____, 19_____

(Your signature)

NOTICE REGARDING WITNESSES

You must use two (2) adult witnesses who will not receive assets under this will. It is preferable to have three (3) adult witnesses. All the witnesses must observe you sign the will, or have you tell them you signed the will, or have you tell them the will was signed at your direction in your presence.

STATEMENT OF WITNESSES

We sign below as witnesses, declaring that the person who is making this will appears to be of sound mind and appears to be making this will freely and without duress, fraud, or undue influence and that the person making this will acknowledges that he or she has read, or has had it read to them, and understands the contents of this will.

(Print Name)

(Signature of Witness)

(Address)

(City) (State) (Zip)

(Print Name)

(Signature of Witness)

(Address)

(City) (State) (Zip)

(Print Name)

(Signature of Witness)

(Address)

(City) (State) (Zip)

Definitions

The following definitions and rules of construction shall apply to this Michigan statutory will:

- (a) “Assets” means all types of property you can own, such as real estate, stocks and bonds, bank accounts, business interests, furniture, and automobiles.
- (b) “Jointly-held assets” means those assets ownership of which is transferred automatically upon the death of 1 of the owners to the remaining owner or owners.
- (c) “Spouse” means your husband or Wife at the time you sign this will.
- (d) “Descendants” means your children, grandchildren, and their descendants.
- (e) “Descendants” or “children” includes persons born or conceived during marriage, persons legally adopted, and persons born out of wedlock who would inherit if their parent died without a will.
- (f) Whenever a distribution under a Michigan statutory will is to be made to a person’s descendants, the assets are to be divided into as many equal shares as there are then living descendants of the nearest degree of living descendants and deceased descendants of that same degree who leave living descendants. Each living descendant of the nearest degree shall receive 1 share. The share of each deceased descendant of that same degree shall be divided among his or her descendants in the same manner.
- (g) “Heirs” means those persons who would have received your assets if you had died without a will, domiciled in Michigan, under the laws which are then in effect.
- (h) “Person” includes individuals and institutions.
- (i) Plural and singular words include each other, where appropriate.
- (j) If a Michigan statutory will states that a person shall perform an act, the person is required to perform that act. If a Michigan statutory will states that a person may do an act, the person’s decision to do or not do the act shall be made in a good faith exercise of the person’s powers. ■

Additional Clauses

(a) Powers of personal representative.

- (1) The personal representative shall have all powers of administration given by Michigan law to independent personal representatives, and the power to invest and reinvest the estate from time to time in any property, real or personal, even though such investment, by reason of its character, amount, proportion to the total estate, or otherwise, would not be considered appropriate for a fiduciary apart from this provision. In dividing and distributing the estate, the personal representative may distribute partially or totally in kind, may determine the value of distributions in kind without reference to income tax basis, and may make non pro rata distributions.
- (2) The personal representative may distribute estate assets otherwise distributable to a minor beneficiary to (a) the conservator, or (b) in amounts not exceeding \$5,000.00 per year, either to the minor, if married; to a parent or any adult person with whom the minor resides and who has the care, custody, or control of the minor; or the guardian. The personal representative is free of liability and is discharged from any further accountability for distributing assets in compliance with the provisions of this paragraph.

(b) Powers of guardian and conservator.

A guardian named in this will shall have the same authority with respect to the child as a parent having legal custody would have. A conservator named in this will shall have all the powers conferred by law. ■

**ADVANCE DIRECTIVES FOR
HEALTH CARE:
MICHIGAN'S PATIENT ADVOCATE LAW**

QUESTIONS AND ANSWERS

Advance Directive for Health Care

1. What is an “advance directive”?

An advance directive is a written document in which a competent individual gives instructions about his/her health care, that will be implemented at some future time should that person lack the ability to make decisions for himself or herself.

2. Must I have an advance directive?

No. The decision to have an advance directive is purely voluntary. No family member, hospital, or insurance company can force you to have one, or dictate what the document should say if you decide to write one.

3. Are there different types of advance directives?

Yes. There are two types, a durable power of attorney for health care and a living will. Living wills are not recognized in Michigan law. However, in case of a dispute as to your health care desires, your written or oral statements regarding your wishes pertaining to health care or the withdrawal or refusal of treatment, may be used as evidence in court, if you are unable to participate in health care decisions. You may wish to consult an attorney for further information regarding durable powers of attorney or living wills.

4. What is a “durable power of attorney for health care”?

A durable power of attorney for health care; also known as a health care proxy, is a document in which you give another person the power to make medical treatment and related personal care and custody decisions for you.

5. Is a durable power of attorney for health care legally binding in Michigan?

Yes, based on a state law passed in 1990.

6. Who is eligible to create a durable power of attorney for health care?

Anyone who is 18 years of age or older and of sound mind is eligible.

7. What is the title of the person to whom I give decision-making power?

That person is known as a “patient advocate.”

8. Who may I appoint as a patient advocate?

Anyone who is 18 years of age or older may be appointed. You should choose someone you trust, who can handle the responsibility, and who is willing to serve.

9. Does a patient advocate need to accept the responsibility before acting?

Yes, he or she must sign an acceptance. This does not have to be done at the time you sign the document. Nevertheless, you should speak to the person you propose to name as patient advocate to make sure he or she is willing to serve.

10. When can the patient advocate act in my behalf?

The patient advocate can make decisions for you only when you are unable to participate in medical treatment decisions.

11. Why might I be unable to participate in medical treatment decisions?

You may become temporarily or permanently unconscious from disease, accident or surgery. You may be awake but mentally unable to make decisions about your care due to disease or injury.

12. Who determines that I am no longer able to participate in these decisions?

Your attending physician and one other physician or licensed psychologist will make that determination. If your religious beliefs prohibit an examination to make this determination, and this is stated in the designation document, you would indicate in the document how it would be determined when the patient advocate can act.

13. What powers can I give a patient advocate?

You can give a patient advocate the power to make those personal care decisions you normally make for yourself. For example, you can give your patient advocate power to consent to or refuse medical treatment for you, to contract for home health care or adult day care; arrange care in a nursing home, or move you to a home for the aged. Note that according to state law, if you were to become incompetent while pregnant, your patient advocate could not authorize a medical treatment decision that would result in your death while pregnant.

14. Can I give my patient advocate the authority to make decisions to withhold or withdraw life-sustaining treatment, including food and water administered through tubes?

Yes, but you must express in a clear and convincing manner that the patient advocate is authorized to make such decisions, and you must acknowledge that these decisions could or would allow your death. If you have specific desires as to when you want to forego life-sustaining treatment, you should make them clear to your advocate. You may also include them as written instructions in your durable power document.

15. Do I have the right to express in the document my wishes concerning medical treatment and personal care?

Yes. You might, for example, express your wishes concerning the type of care you want during terminal illness. You might also express a desire not to be placed in a nursing home and a desire to die at home. Your patient advocate has a duty to try to follow your wishes.

16. Is it important to express my wishes in the durable power of attorney for health care designating document?

Yes. Your wishes might not be followed if others are unaware of them. It can also be a great burden for your patient advocate to make a decision for you without your specific guidance.

17. Can I appoint a second person to serve as patient advocate in case the first-named person is unable to serve?

Yes.

18. Must a durable power of attorney for health care designation document be witnessed?

Yes. Two witnesses must sign. The witnesses must not include your spouse, parent, child, grandchild, sibling, presumptive heir, known devisee at the time of the witnessing, physician, or patient advocate; an employee of your life or health insurance provider; an employee of a health facility that is treating you; or an employee of a home for the aged as defined in section 20106 of the Public Health Code, Act No. 368 of the Public Acts of 1978, being Section 333.20106 of the Michigan Compiled Laws, where you reside.

19. In general, what should I do before completing an advance directive?

Take your time. Consider who you might choose to be your proxy, or to act in your place. Think about your treatment wishes. Discuss the issue with family members and your doctor. Talk with your minister, rabbi, priest, or other spiritual leader if you feel it would be helpful.

20. Are there issues I should give particular attention to?

Yes. Many people have strong feelings about the administration of food and water, either by tube down their throat, a tube placed surgically into their stomach, or intravenously. You may wish to consider and indicate in what circumstances, if any, you wish such procedures withheld or withdrawn. Also, bear in mind that people's opinions regarding their own health care may change over time. Your wishes regarding medical treatment when you are relatively young may be quite different from your wishes when you reach advanced age, so you may wish to review your decisions periodically with your patient advocate.

21. Is there a standard form for an advance directive?

Absolutely not. While this pamphlet contains sample form which you may choose to use to designate a patient advocate, you may use a form designed by an organization, you may hire a lawyer to draft the necessary documentation, or you may write out the document yourself. If you write the documentation yourself, make sure that it is legible. Under state law, you must sign the document, date it, and have it witnessed as described above. A person accepting the responsibility to act as a patient advocate must sign an acceptance to the designation document which contains provisions required by statute.. **(These statutory provisions are listed in sections A through I found in part V of the attached Durable Power of Attorney. for Health Care Form.)**

22. What if there is a dispute as to how my durable power of attorney for health care should be carried out?

If there is a dispute as to whether your patient advocate is acting consistent with your best interest, the probate court may be petitioned to resolve the dispute. The court can remove a patient advocate who acts improperly in your behalf. ■

Guide for Using The Durable Power of Attorney Form

The pages following this guide contain a blank copy of a Durable Power of Attorney for Health. Care form which you may use to designate your patient advocate. This is a suggested form only. Michigan law does not require a specific form to be used. If you wish to provide more details in your durable power document, you may attach additional pages to it containing those details. This guide is intended to help clarify the purposes of the various provisions in this form.

THIS FORM PROVIDES FOR A DURABLE POWER OF ATTORNEY FOR PURPOSES OF CARE, CUSTODY, AND MEDICAL TREATMENT ONLY. IF YOU DESIRE A MORE COMPREHENSIVE DURABLE POWER OF ATTORNEY THAT GRANTS AUTHORITY FOR PURPOSES OF HANDLING FINANCIAL OR BUSINESS AFFAIRS, PLEASE CONSULT AN ATTORNEY.

SECTION I: APPOINTMENT OF ADVOCATE

The first several blanks in the form are for putting your name and the name(s) of persons you are appointing as your advocate or successor advocate. You may appoint ANY person who is at least 18 years of age to be your advocate. It is important that you consult with the person you are naming and secure his or her consent before naming that person.

The law requires that before you can be considered unable to participate in medical treatment decisions, that determination must be made by your attending physician and at least one other physician or a licensed psychologist. Because some individuals religious beliefs may not allow for an examination by a physician, the document can state the religious objection and indicate how it shall be determined when the patient advocate may exercise his or her powers.

SECTION II: GRANTS OF AUTHORITY AND RESPONSIBILITY

This is a crucial section of the durable power document. You may check any, all or none of the grants of power. If you do not check any of the options, you will need to attach your own written grants of power to indicate what powers your advocate will have.

This section contains the very important provision regarding whether decisions to withhold or withdraw treatment which would allow you to die will be made for you. Due to the serious nature of this granting of power, Michigan law requires that you express in a clear and convincing manner that your patient advocate is authorized to make such a decision, and that you acknowledge that such a decision could or would allow your death. If you do grant this authority, you should make clear to your advocate your desires for treatment. Section III of the form provides a space for setting forth your desires.

SECTION III: DESIRES AND PREFERENCES FOR TREATMENT

This is the section of the document where you may state your desires regarding the care, custody and medical treatment you should or should not receive, and under what circumstances treatment should be administered, continued, refused, or withdrawn. Here you may direct your treatment regarding mechanical life-supports (like respirators or kidney dialysis) ordinary or routine treatments (simple surgeries, use of antibiotics, insulin, heart or blood pressure medications, etc.), and basic care (including the provision of food and water). As with the other sections of your durable power document, you may attach additional pages if the space provided is inadequate.

MICHIGAN LAW DOES NOT REQUIRE THAT YOU FILL OUT THIS SECTION OR PROVIDE AN ATTACHMENT ACCOMPLISHING THE SAME PURPOSE. The law stipulates that your advocate must act in your best interests and that health care providers should only comply with your advocate's direction if he or she is reasonably believed to be acting within the authority granted in your designation of the patient advocate. Thus, directions your advocate gives which are consistent with your statement in this section are not likely to be questioned.

SECTION IV: SIGNATURE AND WITNESSING

Michigan law requires that before a patient advocate can execute any of his or her duties and responsibilities, he or she must sign an acceptance to the designation. The first provision of Section IV simply insures that you are aware that this designation must be signed before the power of attorney becomes effective. It also will indicate whether the designation and acceptance process were completed at one time.

Next, your signature is required. Finally, the requirements pertaining to the witnessing of the designation are contained within this section. Please note the limitations on who may serve as a witness.

SECTION V: ACCEPTANCE OF THE DESIGNATION

As noted above, the advocate whom you name must sign an acceptance of your appointment before he or she can act on your behalf. Michigan law requires that certain information regarding the rights, authorities, and limits related to durable power designations be contained within this acceptance. The acceptance provided in Section V of the form meets these requirements.

The name of the person you are appointing should appear in the first blank, and your name (principal) should appear in the second blank. The third blank should contain the date on which you signed your durable power document. The acceptance may be signed on the same day, or at a later time. Finally, your advocate's signature and the date of his or her signing are needed at the end of the acceptance. ■

Durable Power Of Attorney For Health Care

(Please print or type required information)

I. Appointment of Patient Advocate

I, _____
(Your full name)

of _____
(Your complete legal address)

hereby appoint _____
(Person you are appointing)

residing at _____
(Person's complete legal address)

as my patient advocate with the following power to be exercised in my name and for my benefit, for the purpose of making decisions regarding my care, custody and medical treatment. This durable power of attorney shall not be affected by my disability or incapacity, and is governed by Section 700.496 of the Michigan Compiled Laws.

In the event that the above-named patient advocate is unable or expresses an intent not to serve as advocate, I then appoint

_____ residing at _____
(Name of successor) (Legal address)

to serve as my patient advocate.

This durable power of attorney shall be exercisable (check one):

When my attending physician and at least one other physician or licensed psychologist determine upon examination that I am unable to participate in medical decisions.

If my religious beliefs prohibit my examination by a physician or licensed psychologist, then when the following events occur:

(use attached sheet if necessary)

Before the powers granted in this durable power of attorney are exercisable, a copy of it shall be placed in my medical record with my attending physician and if applicable, with the facility where I am located. I retain the right to revoke this durable power of attorney at any time, and by any means whereby I may communicate an intent to revoke it.

II. Grants of Authority and Responsibility

With respect to my physical and medical treatment, I am granting to my advocate the authorities and responsibilities indicated below. Check those you are authorizing and add any additional authorities and responsibilities below. Use more sheets if necessary.

- Access to and control over my medical records and information.

- Power to employ and discharge physicians, nurses, therapists, and any other care providers, and to pay them reasonable compensation.

- Power to give informed consent to receiving any medical treatment or diagnostic, surgical, or therapeutic procedure.

- Power to refuse, or to authorize the discontinuance of, any medical treatment, or diagnostic, surgical or therapeutic procedure.

- Power to refuse, or to authorize the discontinuance of, any medical treatment or diagnostic, surgical, or therapeutic procedure. IN GRANTING THIS POWER, I AUTHORIZE MY ADVOCATE TO MAKE A DECISION TO WITHHOLD OR WITHDRAW TREATMENT THAT WOULD ALLOW MY DEATH. I FURTHER ACKNOWLEDGE THAT SUCH A DECISION TO WITHHOLD OR WITHDRAW TREATMENT COULD OR WOULD ALLOW MY DEATH. I INSTRUCT MY ADVOCATE IN SECTION III, ON THE NEXT PAGE, AS TO MY DESIRES REGARDING THE WITHHOLDING OR WITHDRAWAL OF TREATMENT THAT COULD OR WOULD BRING ABOUT MY DEATH. (If you have checked this item, it is strongly recommended that you use the optional Section III on the next page to specify your desires.)

- Power to execute waivers, medical authorizations, and such other approval as may be required to permit or authorize care which I may need, or to discontinue care that I am receiving.

IV. Signature of Principal

I have discussed this designation with my above-named patient advocate who intends to sign the attached acceptance to this designation (check one):

- Concurrently with the execution of this document.
- At a future date.

I freely and voluntarily sign this document, in the presence of the below-named witnesses, and it shall become effective on the date indicated below.

_____ (Your signature) _____ (Date)

_____ (Print or type full name)

_____ (Address)

_____ (City) _____ (State) _____ (Zip)

ATTESTATION OF WITNESSES

As a witness to the execution of this durable power of attorney, I attest that the person who has signed this document in my presence appears to be of sound mind and under no duress, fraud, or undue influence, I further attest that I am not the person's spouse, parent, child, grandchild, sibling, presumptive heir, known devisee at the time of this witnessing, physician, the named patient advocate, an employee of a life or health insurance provider for the person, or an employee of a health facility that is treating the person or a home for the aged where the person resides.

_____ (First Witness's Signature) _____ (Address)

_____ (Type or Print Name) _____ (City) _____ (State) _____ (Zip)

_____ (Second Witness's Signature) _____ (Address)

_____ (Type or Print Name) _____ (City) _____ (State) _____ (Zip)

V. Acceptance to the Designation of Power of Attorney

I, _____ hereby accept the
(Print patient advocate's name)

responsibilities conferred upon me by _____
(Print principal's name)

to serve as patient advocate in the durable power of attorney document executed on

_____. I maintain the right to revoke this acceptance at
(Date)

any time, and by any means whereby I may communicate a desire to revoke it. By providing my signature below I acknowledge that I have read and understand the requirements of Michigan law pertaining to the execution of a durable power of attorney for health care, set out in sections (A) through (I) below.

- (A) This designation shall not become effective unless the patient is unable to participate in medical treatment decisions.
- (B) A patient advocate shall not exercise powers concerning the patient's care, custody and medical treatment that the patient, if the patient were able to participate in the decision, could not have exercised on his or her own behalf.
- (C) This designation cannot be used to make a medical treatment decision to withhold or withdraw treatment from a patient who is pregnant that would result in the pregnant patient's death.
- (D) A patient advocate may make a decision to withhold or withdraw treatment which would allow a patient to die only if the patient has expressed in a clear and convincing manner that the patient advocate is authorized to make such a decision, and that the patient acknowledges that such a decision could or would allow the patient's death.
- (E) A patient advocate shall not receive compensation for the performance of his or her authority, rights, and responsibilities, but a patient advocate may be reimbursed for actual and necessary expenses incurred in the performance of his or her authority, rights and responsibilities.
- (F) A patient advocate shall act in accordance with the standards of care applicable to fiduciaries when acting for the patient and shall act consistent with the patient's best interests. The known desires of the patient expressed or evidenced while the patient is able to participate in medical treatment decisions are presumed to be in the patient's best interests.
- (G) A patient may revoke his or her designation at any time and in any manner sufficient to communicate an intent to revoke.
- (H) A patient advocate may revoke his or her acceptance to the designation at any time and, in any manner sufficient to communicate an intent to revoke.

(I) A patient admitted to a health facility or agency has the rights enumerated in section 20201 of the public health code, Act No. 368 of the Public Acts of 1978, being Section 333.20201 of the Michigan Compiled Laws.

Some, but not all, of the rights enumerated in Sec. 20201 include:

A patient or resident in a health facility or agency (including a hospital or nursing home) shall not be denied appropriate care on the basis of race, religion, color, national origin, sex, age, handicap, marital status, sexual preference or source of payment.

Patients and residents are also entitled to:

- inspect copies of their medical records and to have the confidentiality of those records maintained.
- receive adequate and appropriate care, and receive information in terms which the patient or resident can understand, about one's medical condition, proposed course of treatment and prospects for recovery, unless medically contraindicated as documented by the attending physician in the medical record.
- refuse treatment to the extent provided by the law and to be informed of the consequences of that refusal. When a refusal of treatment prevents a health facility or its staff from providing appropriate care according to ethical and professional standards, the relationship with the patient or resident may be terminated upon reasonable notice.
- information about the facility's policies and procedures for initiation, review, and resolution of patient complaints.
- receive and examine an explanation of their bills regardless of the source of payment and to receive, upon request, information relating to financial assistance available through the facility.
- associate and have private communications with their physician, attorney, or any other person of their choice, and to send and receive personal mail unopened on the same day it is received at the health facility or agency, unless medically contraindicated as documented by the attending physician in the medical record.

Advocate's Signature

Date

ORGAN DONATION

QUESTIONS AND ANSWERS

Organ Donations

1. How can I be assured that my donation decision will be carried out?

First, discuss your wishes with your family because your next-of-kin will be requested to give consent for donation at the time of your death. Then sign a donor card or driver license sticker in the presence of two witnesses and carry it with you at all times.

2. Can the next-of-kin consent to a donation if the deceased family member has not signed either a donor card or a driver's license?

Yes. The Public Health Code provides for this opportunity.

3. Can my donation decision be included in a will?

Yes. However, since organ donations must occur promptly, this will normally be ineffective because wills are rarely read, let alone probated, until long after the time for the organ donation has passed. Still, the time of making a will may be a good time to discuss donation with family members. The discussion with your next-of-kin is most important.

4. Who can be a donor?

Almost anyone. Poor health, poor eyesight and age do not prohibit you from becoming a donor. However, some of these factors do influence the likelihood of the tissues being suitable for transplant. Organs and tissues that cannot be used for transplants, however, can often be used for research to help scientists find cures or better treatments for serious illness.

5. Will donation affect my funeral arrangements?

No. The donation is performed within hours after death, so funeral arrangements may proceed as planned. Removal of organs leaves no visible signs that would interfere with a normal open casket viewing.

6. Will my family pay or receive any fees for donation?

No. It is illegal to buy or sell human eyes, organs, and tissues.

7. Will the quality of medical treatment be affected if one is a known donor?

Strict laws protect the potential donor. Legal guidelines must be followed before death can be certified. The physician certifying a patient's death cannot be involved in any way with the donation or with the transplant.

8. How can I obtain more information regarding organ, tissue and eye donation?

Contact the Transplantation Society of Michigan at 1-800-482-4881 for a donor card or more information about this life-saving decision. Contact the Michigan Eye Bank at 1-800-247-7725 for questions specific to eye donation. ■

DONATION FORM

fold and mail to: Transplantation Society of Michigan • 2203 Platt Road • Ann Arbor, MI 48104

Questions? Please feel free to call: 313-973-1577 or 1-800-482-4881

Uniform Donor Card

of _____
(Print or type name of donor)

In the hope that I may help others, I hereby make this anatomical gift if medically acceptable, to take effect upon my death. The words and marks below indicate my desires.

I give (a) _____ any needed organs or physical parts

(b) _____ only the following organs or physical parts:

(Specify the organ(s) or physical part(s))

for the purposes of transplantation, therapy, or medical research or education;

(c) _____ my body for anatomical study if needed.

Limitations or special wishes, if any: _____

Signed by the donor and the following 2 witnesses in the presence of each other:

Signature of donor

Date of birth of donor

Date signed

City and state

Witness

Witness

— NOTES —

*The information in this publication is available,
upon request, in an alternative, accessible format.*



Sexuality and Cancer

For the Man Who Has Cancer, and His Partner



©2001, American Cancer Society, Inc. All rights reserved. This booklet is protected by copyright. No part of it may be reproduced in any manner or by any means, electronic or mechanical, without the written permission of the publisher.

This booklet provides general help and is not meant to replace consultation with your doctor or nurse. Resources listed at the end of this booklet are provided for convenience. Inclusion on the list does not imply endorsement by the American Cancer Society. There are many additional materials on various aspects of cancer and cancer treatment that are available from the local office of your American Cancer Society, or on our web site at www.cancer.org or by calling 1-800-ACS-2345.

Any trade names used in this booklet are for convenience only, and do not represent any previous testing or endorsement by the American Cancer Society. Generic and other brands may be substituted as determined by your physician.

The original material for this booklet was prepared for the American Cancer Society by Leslie R. Schover, PhD, Head, Section of Psychosexual Disorders, Clinical Psychologist, Center for Sexual Function, Cleveland Clinic Foundation.

Dr. Schover wishes to acknowledge the following individuals for their support and knowledge: Wendy Schain, EdD, Andrew C. von Eschenbach, MD, Miguel Da Cunha, PhD, Donna Copeland, PhD, Michael Fife, MSW, David Gershenson, MD, Kathy Crosson, MPH, Frankie Ann Holmes, MD, Christopher Logothetis, MD, Dorothy Smith, RN, ET, and Barbara Reschke.

Contents

Introduction	1
What Is a Normal Sex Life?	3
What Is a Healthy Sexual Response?	4
Elements of Male Sexual Desire and Response	5
Keys for Staying Sexually Healthy Despite Cancer Treatment	7
Effect of Cancer Treatment on Male Sexuality	9
Lack of Desire	9
Erection	9
Premature Ejaculation	10
Pain	10
Surgery and Erection	10
Radiation Therapy and Erection	12
Chemotherapy, Sexual Desire, and Erection	13
Hormone Therapy	13
What Are the Psychological Effects of Hormone Therapy?	14
Psychological Effects of Treatment on Erection	15
Cancer Treatment and Ejaculation	15
Surgery and Ejaculation	15
Other Cancer Therapies and Ejaculation	17
Male Sexual Problems Caused by Cancer Treatment	18
<i>Ways of Dealing with Sexual Problems</i>	19
Will a Sexual Problem after Cancer Treatment Be Permanent?	19
Overcoming Temporary Problems	20
Determining the Cause of Problems that Appear to Be Permanent	20

When Is Sexual Counseling Helpful?	21
Is There a Pill that Will Cure Sexual Problems?	21
Can Hormone Therapy Restore Sexual Functioning?	22
Is There a Way to Restore Erections if the Nerves or Blood Supply of the Penis Have Been Damaged?	22
Penile “Prostheses” or Implants	24
Is There a Way to Make Orgasm as Intense as It Used to Be?	26
<i>Special Aspects of Some Cancer Treatments</i>	27
Urostomy or Colostomy	27
Laryngectomy	29
Treatment for Facial Cancers	29
Limb Amputation	30
Loss of One or Both Testicles	30
Penectomy	31
Keeping Your Sex Life Going	33
Coping with Changes in Appearance	33
Changing Negative Thoughts	35
Coping with Outward Effects of Chemotherapy	35
Overcoming Depression	36
Rebuilding Self-Esteem	37
Good Communication	38
Overcoming Anxiety	38
Resuming Sexual Activity with Your Partner	39
Making Intercourse More Comfortable	41
Rekindling Sexual Interest	42
<i>The Single Man with Cancer</i>	43
When to Talk About Your Cancer	44
The Possibility of Rejection	45

Improving Your Social Life	45
<i>Dispelling Myths About Cancer</i>	46
Can Sexual Activity Cause Cancer?	46
Is Cancer Contagious Through Sexual Contact? What About AIDS?	47
Can Sex Be Harmful to a Patient or Partner?	48
When Should a Person with Cancer Not Have Sex?	49
Others' Views of Cancer	50
Advanced Cancer	51
<i>Professional Help</i>	51
Sexual Rehabilitation Programs in Cancer Centers	51
Sexual Dysfunction Clinic Staffs	52
Sex Therapists	52
Other Kinds of Counseling	53
Other Medical Specialists	54
What to Avoid	54
Looking Ahead	54
Resources	55
Books	55
Related Publications	55
Educational Videotapes on Cancer and Sexuality	56
Relaxation Audiotapes	56
Support and Service Organizations	56
Computer-Based Resources	58
<i>American Cancer Society</i>	58
I Can Cope	58
Man to Man	59

Introduction

When you first learned you had cancer, your thoughts probably focused on survival. As soon as treatment began, however, a new question became crucial: How “normal” can your life be, even if cancer is under control? What about sexuality?

Sexuality is an important part of everyday life. Feelings about sexuality affect our zest for living, our self-image, and our relationships with others. Yet patients and doctors often don’t talk about the effects of cancer treatment on sexuality.

In this booklet, we offer information about cancer and sex in the areas that most concern you and your partner. We cannot answer every question, but we hope we can provide enough information to allow you and your partner to talk honestly about your sex life together.

Keep in mind that pleasurable touching between you and your partner is always possible, regardless of the effects of cancer treatment. This may surprise you, especially if you have been feeling down or have not had sex for a while. But it is true. The ability to feel pleasure from touching almost always remains.

The first step is to discuss the topic of sexuality with your doctor or other members of the health care team. You have a right to know how your treatment affects nutrition, pain, and your ability to return to work. You also have a right to know the facts about your sexual health.

Since we probably will not answer all of your questions, we also include a list of resources at the end of the booklet for more information.

We hope this booklet helps you and your loved one fight cancer together, and that you remain as close to each other as possible.

We offer information about cancer and sex in the areas that most concern you and your partner.



What Is a Normal Sex Life?

Sexual practices and beliefs vary widely from person to person. Therefore, defining “normal” is almost impossible. Some couples like to have sex daily. For others, once a month is enough. Many people see oral sex as a normal part of foreplay, but some believe it is not acceptable.

“Normal” for you and your partner is whatever gives you pleasure together. Both partners should agree on how to make their sex life happy.

It is normal for some people with cancer to lose interest in sex at times. Doubts and fears can make you feel less than your best. At times, concern about your health may overshadow your interest in sex.

Once you return to your normal routines, however, your interest in sex can begin to return.

It is also normal to have an interest in sex throughout your life. This is an important point, because most cancers occur more often with age, particularly among those 50 or older. Many people, however, believe that sex is only for the young. Older people are expected to lose their desire for sex and their ability to “perform.”

These beliefs are largely myths. Men and women can remain sexually active until the end of life. No one should ever have to apologize for still having an interest in sex “at my age.” (See the Resources section at the end of this booklet for publications on sex and aging.)

What is normal isn’t always what the media have led us to expect. The media influences our ideas about normal sexuality. Since the 1960s, books, TV, movies, and magazines have become more sexually explicit. For the most part, Americans have benefited from having more information about sex. But, the media has also promoted some unrealistic standards of “good sex.” Men believe they are expected to have instant erections. Women feel inferior if they fail to reach orgasm at least once in every session of lovemaking. If you find yourself feeling

inadequate, remember that the only true measure of your worth as a lover is the pleasure you and your partner find together.

Sexuality is one aspect of our need for closeness, touch, playfulness, caring, and pleasure. Even when sex becomes impractical, such as during a severe or terminal illness, physical expression of caring remains an important way of sharing closeness.

What Is a Healthy Sexual Response?

The sexual response of both men and women is a cycle with four phases:

- desire
- excitement
- orgasm
- resolution

To complete the cycle, the phases must be experienced in that order. The cycle can, however, be stopped at any phase. You don't have to reach orgasm each time you feel a desire for sex.

Desire is an interest in sex. You may just think about sex, feel attracted to someone, or feel frustrated because of a lack of sex. Sexual desire is a normal part of life from the teenage years onward.

Excitement is the phase when you feel aroused or "turned on." Touching and stroking feel much more intense when a person is excited. Excitement also results from sexual fantasies and erotic sights, sounds, scents, and tastes. Physically, excitement means that:

- the heartbeat and pulse speed up
- blood pressure rises
- breathing gets "heavy"
- blood is sent to the genital area
- the surge of blood creates an erection-a stiff penis
- the skin of the genitals turns a deeper color

In a woman, the vagina becomes moist and increases in both depth and width, like a balloon.

Orgasm is the sexual climax. In both men and women, the nervous system creates intense pleasure in the genitals. The

muscles around the genitals contract in rhythm, sending waves of feeling through the body. In men, these muscle contractions cause ejaculation of semen. Most researchers do not believe that women ejaculate a fluid at orgasm.

Resolution is the return of the body to its unexcited state. Heartbeat and breathing slow. Blood drains out of the genital areas. Mental excitement subsides.

Resolution occurs within a few minutes after an orgasm. If a person becomes excited but does not reach orgasm, resolution still takes place, but more slowly. It is not harmful to become excited without reaching orgasm, though it may feel frustrating. Some men and women may feel a mild ache until the extra blood leaves the genital area.

Men have a “refractory period,” a time after one orgasm in which a man is not physically able to have another one. This time tends to get longer as a man ages. A man in his 70s may need to wait several days between sexual encounters. Women do not have a refractory period. Many can have “multiple orgasms,” one after another.

Elements of Male Sexual Desire and Response

Testosterone is the primary male hormone. This hormone causes the reproductive organs to develop, and promotes erections and sexual behavior. It also is responsible for secondary sexual characteristics, such as voice deepening and beard growth. The testicles produce most of this hormone. Adrenal glands, which sit atop the kidneys, also produce lesser amounts in men and women.

The hypothalamus region of the brain controls the amount of hormones produced. When the testosterone level gets low, the hypothalamus signals the pituitary gland at the base of the brain. The pituitary sends a hormone messenger through the bloodstream to tell the testicles to speed up production.

Men’s hormone levels vary widely, but most men have more circulating testosterone than they need. A man with a low level of testosterone could have trouble getting or keeping erections and may lose his desire for sex. In the healthy man, hormone problems are rare. More often, anxiety causes erection prob-

lems. Other common medical causes for erection problems include problems with the blood vessels or nerves in the pelvic area.

An erection occurs when the brain sends a signal down the spinal cord and through the nerves that sweep down into the pelvis. Some of these important nerves run along the outside of the prostate gland.

The spongy tissue inside the shaft of the penis relaxes and the arteries that carry blood into the penis expand when the signal for erection travels through the nervous system. As the walls of the arteries stretch, blood races into the penis at up to 50 times its usual speed. The blood fills two spongy tubes of tissue inside the shaft of the penis. The veins in the penis, which normally drain blood out of the penis, squeeze shut, slowing the drainage process. The result is a great increase in blood pressure inside the penis and a firm erection.

The nerves that allow a man to feel pleasure when the penis is touched run in a different path from the nerves that control blood flow. Even if nerve damage or blocked arteries prevent a man from getting erections, he can almost always feel pleasure from being touched. He can also still reach orgasm.

A third set of nerves, which runs higher up in a man's trunk controls ejaculation of semen. Ejaculation is somewhat hard to understand. It is the second stage of orgasm.

A man's orgasm has two stages. In the first stage, called emission, the prostate, seminal vesicles, and vas deferens (tubes joining the testicles with the seminal vesicles) contract. This action mixes the sperm cells and the fluid that makes up the semen. The testicles produce the sperm cells. Semen, a whitish protein-rich fluid made by the prostate and seminal vesicles, nourishes the sperm cells and keeps them alive. This mixture is deposited at the top of the urethra (the tube running through the penis), ready to be ejaculated. A man feels emission as "the point of no return," when he knows he is about to have an orgasm. Emission is controlled by the "sympathetic" or involuntary nervous system.

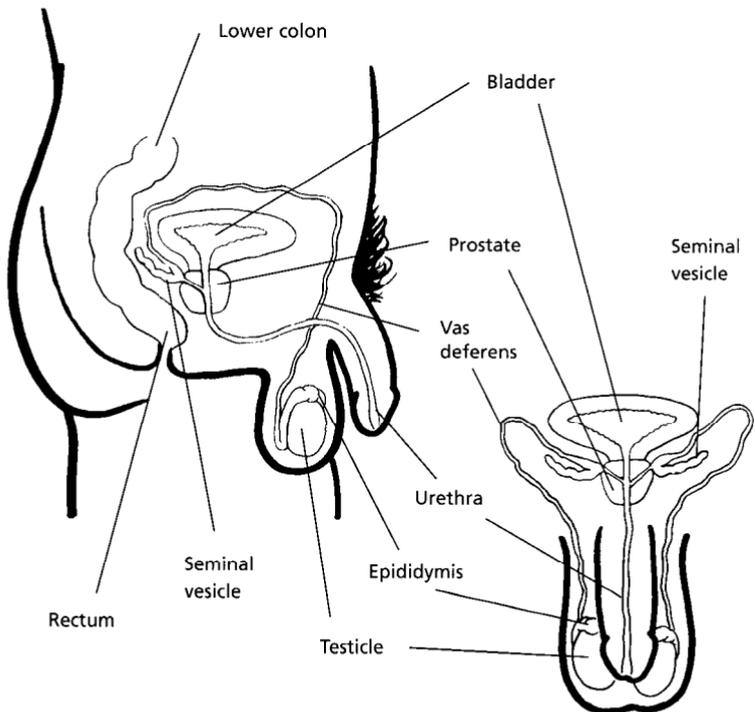
The second stage is ejaculation. Ejaculation is controlled by the same nerves that carry pleasure signals when the genital area is caressed. Those nerves cause the muscles around the base of

the penis to squeeze in rhythm, pushing the semen through the urethra and out of the penis. At the same time, messages of pleasure are sent to the man's brain. This sensation is known as orgasm or climax. The drawings below show the male sex organs.

Keys for Staying Sexually Healthy Despite Cancer Treatment

Here are some points to keep in mind as you try to continue your sex life during or after cancer treatment:

1. Gather as many facts as you can about the usual effects of your cancer treatment on sexuality. Talk with your doctor, nurse, or any other member of your health care team. When you know what to expect, you can plan ways to handle those issues.



2. Keep in mind that, no matter what kind of cancer treatment you have, you will almost always be able to be intimate and feel pleasure from touching. For example, some types of treatment can damage a man's ability to have erections. Few cancer treatments (other than those affecting some areas of the brain or spinal cord) damage the nerves and muscles involved in feeling pleasure from touch and reaching orgasm. Most men who cannot have erections or produce semen can still have the feeling of orgasm with the right kind of touching. This stubborn survival of the orgasm makes it worthwhile for people with cancer to try sexual touching. Pleasure and satisfaction are possible, even if some aspects of sexuality have changed.

3. Try to keep an open mind about ways to feel sexual pleasure. Some couples have a narrow idea of what is "normal" in sex. If both partners cannot reach orgasm through or during penetration, they feel cheated. For people treated for cancer, however, there may be times when intercourse is not possible.

Those times can be a chance to learn new ways to give and receive sexual pleasure. You and your partner can help each other reach orgasm through mutual touching and stroking. At times, just cuddling can be pleasure enough. You could also continue to enjoy self-stimulation. Do not deny yourself other ways of showing caring and feeling alive, just because your "normal" routine has been disrupted.

4. Strive for good communication about sex with your partner and with your doctor. The worst enemy of sexual health is silence. If you are too embarrassed to ask your doctor whether you can resume sex, you may never find out. Talk to your doctor about sex and tell your partner what you learned. Otherwise, your partner may fear that sex might hurt or harm you.

Good communication is also the key to changing your sexual routine when cancer changes it. If you feel weak or tired and want your partner to take a more active role in touching you, say so. If some part of your body is tender or sore, you can guide your mate's touches to create the most pleasure and avoid pain.

Effect of Cancer Treatment on Male Sexuality

Lack of Desire

Both men and women often lose interest in sex during cancer treatment, at least for a time. At first, concern for survival is so overwhelming that sex is far down on the list of needs to be met. This is quite normal.

After treatment has begun, there may still be little interest in sex. Loss of desire may result from worry and depression, from nausea, or from pain. Cancer treatments that disturb the normal hormone balance can also lessen sexual desire.

If there is a conflict in the relationship, one partner or both might lose interest in sex. Any emotion or thought that keeps a man from feeling excited can also interfere with his getting or keeping an erection. The most common anxiety is a nagging fear of not being able to get an erection or satisfy a partner. Many people who have cancer worry that a partner will be turned off by changes in their bodies or by the very word cancer.

Each part of a man's sexual cycle has some independent functioning. That is why, after some types of cancer treatment, a man may still desire sex and be able to ejaculate, but not have an erection. Other men have the feeling of orgasm along with the rhythmic muscle contractions, even though semen is no longer ejaculated.

Erection

Cancer treatments can interfere with erection by damaging a man's pelvic nerves, pelvic blood vessels, or hormone balance. Sometimes these side effects cannot be avoided if cancer is to be controlled. Following cancer treatment, medical or surgical treatments can often restore erections.

Premature Ejaculation

Premature ejaculation means reaching a climax too quickly. Men who are having erection problems often lose control over the ability to delay orgasm, so they ejaculate too quickly.

Premature ejaculation is a very common problem, even for healthy men. It can be overcome with some practice in slowing down excitement (see the book *The New Male Sexuality* listed in the Resources section).

Some men also feel that their orgasm is weaker than before. A mild decrease in the intensity of orgasm is normal with aging, but it can be more severe in men whose cancer treatments interfere with ejaculation of semen.

Pain

Men also sometimes feel genital pain during sex. Irritation of the prostate gland or urethra from cancer treatment can cause painful ejaculation. Pain in the penis as it becomes erect is less common, but in men over 40, the penis may develop a painful curve or “knot” with erection. However, this condition, called Peyronie’s disease, does not seem to be any more common in men with cancer. Promptly tell your doctor about any pain in the genital area.

Surgery and Erection

Several types of cancer surgery can interfere with erections. These include:

- Radical prostatectomy—the removal of the prostate and seminal vesicles for prostate cancer.
- Radical cystectomy—the removal of the bladder, prostate, upper urethra, and seminal vesicles for bladder cancer, requiring a new way of collecting urine through a urostomy into an external pouch or by rebuilding a new “bladder” internally.
- Abdominoperineal (A-P) resection—the removal of the lower colon and rectum for colon cancer, often requiring a colostomy.

- Total pelvic exenteration—the removal of the bladder, prostate, seminal vesicles, and rectum, usually for a large tumor of the colon, requiring both a urostomy and a colostomy.

All of these operations can damage the nerves that control blood flow to the penis. Damaging the nerves is like fraying a telephone wire—the message to start an erection is either weakened or completely lost. The nerves surround the back and sides of the prostate gland, lie close to the rectum behind it, and fan out like a cobweb around the prostate. Therefore, during surgery the doctor may not be able to see the nerves and may damage them.

A new way to remove the prostate while sparing the nerves has been developed. Some surgeons are even trying to locate the nerves by using a mild electric current to find the spot where stimulating a nerve will cause an erection. When the size and location of a tumor are right for nerve-sparing surgery, more men recover erections than with other techniques. Nerve-sparing is sometimes used in radical prostatectomy, radical cystectomy, or A-P resection.

Some of the damage to erections after these operations may be caused by a loss of blood flow to the penis. The surgeon must seal off some of the small arteries that feed into the two main blood vessels involved in erection. Blood flow then is slowed, like a river after streams that run into it have been dammed. Usually a man has partial erections after such surgery. His penis swells when he feels excited. The penis does not become firm enough to enter a woman's vagina. Skin sensation and the ability to feel an orgasm should, however, remain normal.

Some men do regain full erections, but it can sometimes take up to a year. We do not know why some men regain full erections and others do not. Men are more likely to recover erections when nerves on both the left and right sides of the

Some men do regain full erections, but it can sometimes take up to a year.

prostate are spared. The healing and growth of new blood vessels may also help restore blood flow to the penis.

Some operations cause more problems with sexual function than others. We do not know of any man who has regained full erections after total pelvic exenteration. This surgery is so rare, however, that statistics are not available. At least 15% of men who have standard cystectomy or prostatectomy have full erections again, and surgeons report better recovery rates after sparing the nerves. After A-P resection, recovery of erections also occurs more often.

Generally, the younger a man is, the more likely he is to regain full erections. Men under 60, and especially under 50, have much higher recovery rates than older men.

Men who had good erections before cancer surgery are far more likely to have a full sexual recovery than are men who had erection problems.

Radiation Therapy and Erection

Radiation therapy to the pelvis is often given to treat prostate, bladder, or colon cancer. It can also cause problems with erections. The higher the total dose of radiation and the wider the section of the pelvis irradiated, the greater the chance that an erection problem will develop.

Radiation affects erection by damaging the arteries that carry blood to the penis. As the irradiated zone heals, internal tissues become scarred. The walls of the arteries lose their elasticity. The walls can no longer expand enough to let blood speed in and create a firm erection. Radiation also can accelerate hardening of the arteries (arteriosclerosis), narrowing, or even blocking the pelvic arteries.

A reasonable estimate is that a quarter to a third of the men who receive radiation notice a change for the worse in their erections. This change most often develops slowly over the first year or so after radiotherapy. Some men continue to have full erections but lose them before reaching climax. Others no longer get firm erections at all. Men who have hypertension (high blood pressure) or who have been heavy smokers seem to be at greater risk for these erection problems. This is because their arteries may already be mildly damaged.

In a small group of men, testosterone production slows after pelvic radiation. The testicles are affected either by a mild dose of scattered radiation or by the general stress of cancer treatment. If a man notices erection problems or a loss of desire after cancer treatment, he may decide to have a blood test for testosterone. However, testosterone levels usually recover within 6 months after radiation therapy, so extra hormones may not be needed. A man with prostate cancer should not take replacement testosterone, since it can speed up the growth of prostate cancer cells.

Chemotherapy, Sexual Desire, and Erection

Most men on chemotherapy still have normal erections. However, a few do develop problems. Erections and sexual desire often decrease just after a course of chemotherapy but recover in a week or two.

Chemotherapy can sometimes affect sexual desire and erections by slowing down the amount of testosterone produced. Some of the medications used to prevent nausea during chemotherapy can also upset a man's hormonal balance, but hormone levels should return to normal after treatments have ended.

A few chemotherapy drugs, for example cisplatin or vincristine, can permanently damage parts of the nervous system. It may be that these drugs interfere with the nerves that control erection. However, there is no scientific proof for such a side effect.

Hormone Therapy

Treatment for prostate cancer that has spread beyond the gland often involves changing a man's hormone balance. This can be done in the following ways:

- by removing a man's testicles
- by giving him different hormones
- by a combination of the two treatments

The goal is to starve the cancer cells of testosterone.

Bilateral orchiectomy, an operation to remove both testicles, greatly reduces a man's testosterone levels. Taking estrogen ("female" hormones) or special medications that shut off the production of testosterone or block testosterone from target cells are alternatives that allow many men to keep their testicles.

All of these treatments have similar sexual side effects. The most common problem is a decrease in desire for sex. Perhaps this is why men often have trouble getting or keeping erections or reaching orgasm. There can be minor changes in appearance due to estrogen therapy. However, most people cannot notice a difference. (See the information under Loss of One or Both Testicles, in the section, Special Aspects of Some Cancer Treatments.)

A number of men receiving hormone therapy say that their desire is still strong. They do, however, have a problem achieving erection. The effects of hormones on the erection response are not well understood, and the side effects of hormones are unpredictable. Some men are able to feel desire and have erections and orgasms, even without testosterone. Other men function well for several years, then slowly lose interest in sex. The motivation to stay sexually active may be the key.

What Are the Psychological Effects of Hormone Therapy?

Men who have lost their testicles or who are on hormone therapy often feel like "less of a man." They fear becoming feminine in looks and personality. This is a myth. Manhood does not depend on hormones, but on a lifetime of being male. Hormone therapy for prostate cancer may decrease a man's desire for sex. However, it cannot change the type of sexual activity he desires. A man who has always been attracted only to women does not suddenly or gradually become homosexual.

Manhood does not depend on hormones, but on a lifetime of being male.

Psychological Effects of Treatment on Erection

Fears about self-image and performance can sometimes lead to erection problems. Instead of “letting go” and feeling excited, a man watches himself during sex to see if he will be able to function. His fears of failure can become a self-fulfilling prophecy. He then blames the resulting problem on his medical condition, although he might have an erection if he is able to relax.

Sex therapy is often successful in treating erection problems caused by anxiety. Treatment for an erection problem should be based on the results of a thorough evaluation. This evaluation should include both interviews and special medical tests.

Cancer Treatment and Ejaculation

Cancer treatment can interfere with ejaculation by damaging the nerves that control the prostate, seminal vesicles, and opening to the bladder. It can also stop production of semen in the prostate and seminal vesicles. Despite this damage, a man can still feel the sensation of pleasure that makes an orgasm. At the moment of orgasm, however, little or no semen spurts out.

Some men say an orgasm without semen feels totally normal. Many others say the orgasm does not feel as strong, long-lasting, or pleasurable. Men often worry that their partners will miss the semen. In fact, most women cannot feel the actual fluid release, so no pleasure is lost for them.

Some men’s chief concern is that orgasm is less satisfying than before. Others are upset by “dry” ejaculation because they wish to father a child.

Surgery and Ejaculation

Two cancer surgeries involve removal of the prostate gland and the seminal vesicles:

- radical prostatectomy
- cystectomy

A man no longer produces any semen after these surgeries. The sperm cells made in his testicles ripen, but then the body

simply reabsorbs the sperm cells with no ill effects. After these cancer surgeries, a man will have a “dry” orgasm, without semen.

Other operations cause retrograde ejaculation. At the moment of orgasm, the semen shoots backward into the bladder rather than out through the penis. This is because the valve between the bladder and urethra remains open after some surgical procedures. This valve normally shuts tightly during emission. The path of least resistance for the semen then becomes the backward path into the bladder. If a man urinates after such a “dry” orgasm, his urine looks cloudy because the semen mixes into it during the dry orgasm.

A transurethral resection is the operation to core out the prostate by passing a special scope into it through the urethra. This usually causes retrograde ejaculation by damaging the bladder valve. This procedure is not a cancer treatment, but sometimes it is used to diagnose cancer.

Two cancer operations can cause “dry” orgasm by damaging the nerves that control emission. These are:

- abdominoperineal (A-P) resection which removes the rectum and lower colon
- retroperitoneal lymph node dissection which removes lymph nodes in the abdomen, usually in men who have testicular cancer.

Some of the nerves that control emission run close to the lower colon and are damaged by A-P resection. The lymph node dissection damages the nerves higher up, where they surround the aorta (the central artery in the abdomen).

The effects of the two operations are probably similar. However, more is known about sexual function after node dissection. Sometimes the node dissection only causes retrograde ejaculation. However, it usually paralyzes emission. When this happens, the prostate and seminal vesicles cannot contract to mix the semen with the sperm cells. In either case the result is a dry orgasm. The difference between no emission at all and retrograde ejaculation becomes important if a man wants to father a child. Retrograde ejaculation is better, because sperm cells may be recovered from a man’s urine and used to make a woman pregnant.

Sometimes nerves recover over time from the damage caused by retroperitoneal lymph node dissection. It often takes one to three years before ejaculation of semen resumes, if at all. Because men with testicular cancer are often young and have not finished having children, surgeons have nerve-sparing techniques that often allow ejaculation to remain normal after retroperitoneal node dissection. Some medications can also temporarily restore ejaculation of semen to allow conception. If sperm cells cannot be recovered from a man's semen or urine, infertility specialists may be able to retrieve them directly from the testicle by minor surgery, then use them in in vitro fertilization to produce a pregnancy. Retroperitoneal node dissection does not stop a man's erections or ability to reach orgasm. However, his pleasure at orgasm may be less intense.

Other Cancer Therapies and Ejaculation

Some cancer treatments slow down the amount of semen that is produced. After radiation to the prostate, some men ejaculate only a few drops of semen. Toward the end of radiation treatments, men often feel a sharp pain as they ejaculate. The pain results from irritation in the urethra (urinary tube through the penis); it should fade within several weeks after the end of treatment.

Usually, men who have hormone therapy for prostate cancer also produce less semen than before.

Chemotherapy rarely affects ejaculation; however, a few drugs may cause retrograde ejaculation by damaging the nerves that control emission. Vincristine is one of these drugs.

The table on page 18 provides a summary of some of the cancer treatments for men and their effects on sexuality and fertility.

Male Sexual Problems Caused by Cancer Treatment

Treatment	Low Sexual Desire	Erection Problems	Lack of Orgasm	Dry Orgasm	Weaker Orgasm	Infertility
Chemotherapy	S	R	R	R	R	O
Pelvic radiation therapy	R	S	R	R	S	O
Retroperitoneal lymph node dissection	R	R	R	O	S	O
Abdominoperineal (A-P) resection	R	O	R	O	S	S*
Radical prostatectomy	R	O	R	A	S	A
Radical cystectomy	R	O	R	A	S	A
Total pelvic exenteration	N	O	R	A	S	A
Partial penectomy	R	R	R	N	R	N
Total penectomy	R	A	S	N	S	U*
Orchiectomy (removal of one testicle)	R	R	N	N	N	R**
Orchiectomy (removal of both testicles)	O	O	S	S	S	A
Hormone therapy for prostate cancer	O	O	S	S	S	A

Key: A=Always N=Never O=Often
R=Rarely S=Sometimes U=Usually

*Artificial insemination of a spouse with the man's own semen may be possible.

**Infertile only if remaining testicle is not normal.

Ways of Dealing with Sexual Problems

Will a Sexual Problem after Cancer Treatment Be Permanent?

Many sexual problems that men have after cancer treatment will not last long. For instance, pain with erection or ejaculation soon after pelvic surgery or radiation will probably disappear. The stress of treatment can also reduce hormone levels for a few weeks. This may cause decreased desire or problems with erection.

As you feel more in control of your body and your life, you will find that your self-confidence returns and your sex life gets better.

Unfortunately, some cancer treatments can permanently alter a man's sexual function. It's hard to know what will happen to any one person. For example, one man may regain erections after radical prostatectomy while another man may not. If you do develop a sexual problem, your health care team can often find the cause and give you an idea of your chance for recovery.

One clue that a problem is a medical one and permanent is if it occurs in all situations. Otherwise, it may be psychological and temporary. For example, if you have trouble getting or keeping an erection, does it happen every time you have sex? Can you get better erections when you relax, when you stimulate your own penis, or when you unexpectedly see someone attractive? If you have a few partners, are your erections better with one of them than with the others?

Many sexual problems that men have after cancer treatment will not last long.

Overcoming Temporary Problems

As men age or go through health problems, feelings of excitement no longer lead to an instant erection. Perhaps you just need more time and stroking to get aroused.

If you have trouble reaching orgasm during sex, perhaps you have not found the right kind of caressing to use. You might even consider buying a hand-held electric vibrator. A vibrator can provide very intense stimulation. Try having a sexual fantasy, or looking at erotic stories or pictures. The more excited you are, the easier it is to reach orgasm.

A number of men have their first orgasm after cancer treatment while asleep, during a sexual dream. If this happens to you, it is proof that your equipment is in working order. Because sleep erections aren't affected by mood or state of mind, they provide a measure of the best erection a man's body can produce. Now it is up to you to set things in motion during your waking sex life.

Determining the Cause of Problems that Appear to Be Permanent

Give yourself several months to recover from treatment and try several ways to overcome your problem. If the problem doesn't go away, special medical tests can be given to learn the cause.

One of the exams used most often takes place while you sleep. Your doctor may send you for two or three nights to a sleep laboratory to check your sleep erections. A technician watches your brain waves and breathing during the night to make sure that your sleep patterns are normal. At the same time, elastic loops placed around the base and tip of your penis are connected to a recorder. The recorder measures changes in the size of your penis during the night. If your sleep erections are firm and long-lasting, your problem should respond well to some sexual counseling. If your sleep erections are poor or you don't have an erection, you may need surgery or a medical treatment to correct the problem.

Since sleep laboratory evaluations are expensive, most doctors use other ways to screen sleep erections. Many send a man home with an electronic monitor to wear on the penis at night. This can be a very good test. A less accurate test is to use a

plastic strip (“snap-gauge” by Dacomed). The patient wears it around the shaft of the penis during sleep. An erection breaks one to three cellophane snaps on the gauge, depending on the firmness of the erection.

Other tests, done in a doctor’s office, can measure blood pressure and pulse in your penis. These tests look for a block in circulation that could be causing the erection problem. Many of these tests include injecting medication into the shaft of the penis. This can produce an erection. Then special ultrasound tests or x-rays can be done. Tests of the reflexes in the genital area are sometimes done. Also common are blood tests to check the levels of the two hormones most closely linked to men’s sexual function, testosterone and prolactin.

When Is Sexual Counseling Helpful?

Any sexual problem caused by anxiety can respond to the counseling that a sex therapist provides. For men, problems caused by anxiety can include:

- loss of sexual desire
- erection problems without a medical basis
- trouble reaching orgasm
- premature ejaculation

When a medical condition limits a man’s sexual function, sex therapy can still be helpful. However, the goals may change. For example, instead of expecting a man to regain full erections, the therapist may help him and his partner learn to enjoy sexual caressing without erections. Sex therapists are also becoming involved in helping men and their partners decide whether to have medical or surgical treatments for erection problems. (See the section on Professional Help.)

Is There a Pill that Will Cure Sexual Problems?

In March of 1998, the Food and Drug Administration (FDA) approved a medication called sildenafil citrate (Viagra) for the treatment of impotence. Viagra helps the body’s ability to achieve and maintain an erection during sexual stimulation by increasing blood flow to the penis. Between 50% and 70% of men with impotence due to medical (rather than psychologi-

cal) problems are helped to some extent by Viagra. Initial studies suggest that nerve damage due to prostate cancer treatment may not respond quite as well as some other physical causes of impotence, but more research in this area is needed. There are several drugs known to interact with Viagra. For example, nitrates, drugs used often as treatment for heart disease, may interact with Viagra to cause very low blood pressure, a complication that can be fatal. In addition to Viagra, several other new drugs for impotence may soon be available. Be sure to ask your doctor about these new medications.

Can Hormone Therapy Restore Sexual Functioning?

In the rare cases that a man has a hormone imbalance, hormone therapy can restore his desire and erections. However, hormones are too often used without careful thought. Most men, even after age 50 or 60, have enough testosterone. Giving extra hormones will not cure a sexual problem. In fact, it can have serious side effects.

In addition, extra testosterone could cause undetected prostate cancer to grow and spread. Men with a history of prostate cancer are never advised to take testosterone pills or shots, even if their own hormone levels are low. Hormone therapy is most helpful as a temporary way to restore sexual desire and erections in men who have damaged testicles from large doses of radiation or chemotherapy. Only a few men, however, really need extra hormones.

Is There a Way to Restore Erections if the Nerves or Blood Supply of the Penis Have Been Damaged?

If the cause of an erection problem is simply a blockage of the arteries that bring blood to the penis, some new operations are available. The surgeon can take an artery that usually supplies the abdominal wall and reroute it by connecting it to the tiny blood vessels inside the penis. Follow-up results so far have been disappointing: only about a quarter of the men have had long-term improvement in their erections.

During the first 3 to 12 months after radical prostatectomy, most men will not be able to get a spontaneous erection and

New research explores transplanting nerves to restore erections, but further research is needed to determine its success.

will need to use medications or other treatments if they wish to have an erection. The effect of this operation on a man's ability to achieve an erection is related to his age and whether nerve-sparing surgery was done. Nearly all men who have a radical prostatectomy should expect some decrease in their ability to have an erection, but younger men may expect to retain more of their ability. After standard radical prostatectomy, between 65% and 90% of men will become impotent, depending on their age.

If surgery does not remove the nerves on either side of the prostate, the impotence rate drops to between 25% and 30% for men under 60. But impotence occurs in 70% to 80% of men over 70, even if nerves on both sides are not removed. After surgery, the sensation of orgasm should continue to be pleasurable, but there is no ejaculation of semen. In other words, the orgasm is "dry".

New research explores transplanting nerves to restore erections, but further research is needed to determine its success. Surgical techniques are also being improved through use of nerve stimulation so that surgeons can avoid cutting nerves needed for erections. Surgery to remove veins that allow too much blood to drain out of the erect penis has had only very limited success.

Though surgery to correct blood flow problems has been disappointing, two nonsurgical treatments have become widely used: penile injection therapy and vacuum devices. Many urologists teach men to inject their own penis with medications that produce erection. Medicine is injected into the side of the shaft of the penis through a very small needle, a few minutes before starting sexual activity. The combination of sexual excitement and medication helps to produce a firmer and longer lasting erection than was occurring before. Penile injection can have side effects. A few men may get an erection that will not go down. If this happens, the man needs to go to an emergency room right away for treatment. Some men develop scarring in

the spongy tissue of the penis after repeated injections. Scarring is often not noticed by the man, but in severe cases can make erections permanently curved. The only way to treat severe scarring is by reconstructive surgery on the penis.

A new way of delivering the same medication used for penile injections is to have a man use an applicator to insert a tiny pellet into his urethra (urinary tube). As the pellet melts, the medication is absorbed through the lining of the urethra and enters the spongy tissue of the penis. Although this system may be more convenient than injections, it is not always as effective and can produce similar side effects.

Another treatment, the vacuum erection device, is less risky, but also may interrupt lovemaking more than an injection does. A man places a plastic cylinder over his penis and pumps out air to produce a vacuum around the outside of the penis. The suction draws blood into the inside of the penis, filling up the spongy tissue. When the penis is firm, the man takes the pump off, slipping a stretchy band onto the base of his penis to help it stay erect. The band can be left on the penis for up to half an hour. Some men use the pump before starting sexual touching, but others find it works better after some foreplay has produced a partial erection. The erection from a vacuum device is usually firm, but may swivel at the base of the penis, limiting comfortable positions for intercourse. It may take some practice to learn how to use a vacuum device properly. Although most vacuum devices are prescribed by physicians, the FDA has approved one that is available over-the-counter.

When injections or a vacuum device are suggested, some sexual counseling can help a couple discuss their options and plan how to make the new treatment a comfortable part of their sex life.

Penile “Prostheses” or Implants

Surgery to implant a “prosthesis” in the penis was the first really successful treatment for medical erection problems. Over the past 20 years, many of these operations have been done, and they are still one of the most effective ways to treat a permanent erection problem. Several types of prostheses are now in use. For one type, two silicone rods are placed into the spongy tissue of the penis.

The result is a penis that hangs out about 45 degrees from the body and always stays about 80% erect. Since it is above the urethra, the prosthesis does not affect urination. Most semi-rigid prostheses now are easily shaped. A metal core runs through each rod. When you bend the penis up or down to conceal it during nonsexual activities, it stays bent. With any of the semirigid prostheses, a man can avoid an embarrassing bulge at his crotch by wearing briefs made for athletics, with heavier-than-normal elastic in front.

The inflatable penile prosthesis offers the choice of a soft or hard penis. It is a pump system placed entirely inside a man's body. Two tough inflatable silicone cylinders are placed inside the penis just as the rods are in the semirigid implant. A balloon-shaped reservoir which contains a mixture of salt water and x-ray dye is tucked behind the groin muscles. A pump is placed inside the loose skin of the scrotal sac. All the parts are connected with tubing.

Usually, the salt water fills the reservoir, leaving the cylinders in the penis empty. From the outside, the penis looks as it normally does when not erect, except it is always a little fuller. When you are ready for sex, you stiffen the penis by squeezing the pump under the skin of the scrotum several times. The salt water flows into the cylinders. This inflates the penis like blood does in a natural erection. When you have finished sexual activity and no longer want an erection, you press a release valve on the bottom of the pump. The cylinders will deflate. The salt water then returns to its reservoir and your penis becomes soft.

A simpler two-piece inflatable prosthesis is a compromise between the semirigid and multiple component inflatable types. It simply has two cylinders that connect to a unified pump and reservoir placed in the scrotal sac. The two-piece inflatable cannot produce as long or thick an erection as the newest multi-part inflatable. When the penis is not inflated, it will be softer than with a semirigid prosthesis, but not as soft or small as with a multi-part inflatable.

Men in poor health are advised to try the semirigid or two-piece inflatable types, since the risk of future problems is so low and the surgery so minor. However, a man who has repeated superficial bladder tumors may need an inflatable

prosthesis because the semirigid rods interfere with cystoscopy. A man who is physically active, either on the job or in his leisure time (jogging, playing tennis, riding), may be more pleased with an inflatable type, since it does not get in the way as much.

If you are seriously considering prosthesis surgery, you might read the chapters on medical and surgical treatments in the books listed in the Resources section.

Married men or those in a committed relationship should include their partner in any decision about implants. Your partner needs to understand the procedure and to have a chance to discuss any fears or questions with your surgeon. You, yourself, must be realistic about what a prosthesis can and cannot do for you. Any penile prosthesis is just a mechanical stiffener for the penis. Having a penile implant cannot solve any other problems, such as low sexual desire, lack of sensation on the skin of the penis, or trouble reaching orgasm. It cannot transform a poor sexual relationship into a great one.

A couple needs to communicate openly the first time they have sex after prosthesis surgery. You may need to experiment with different kinds of touching, or with positions for intercourse. Make sure you are truly excited before trying to have intercourse, rather than starting sex just because your penis is erect. Couples who have maintained mutual touching, even if an erection problem prevented penetration, adjust more easily to the prosthesis.

Is There a Way to Make Orgasm as Intense as It Used to Be?

Some men treated for cancer notice that their orgasms become weaker or last a shorter time than before. Sometimes a mildly weaker orgasm is just part of normal aging. As men age, the muscle contractions at climax are no longer as strong. More severe weakening of orgasm often goes along with erection problems and may be caused either by anxiety or by damage to the nervous system. In those cases, treating the erection problem may not improve a man's orgasms. Men who have dry orgasm after cancer treatment also sometimes say they have reduced sensation.

Few medications can increase the strength of a man's climax. Those that do have dangerous side effects or may stop working after a few doses. Some common-sense advice is to make sure you are as excited as possible during sex. Focus on your sensations of pleasure or on an arousing fantasy and take a long time for foreplay. If you find yourself getting close to orgasm, ask your partner to "tease" you a little by slowing down the caresses. Let your excitement die down and rebuild several times before you actually climax.

You can practice this teasing technique during your own self-stimulation, too. When you feel your excitement is high, stop touching your penis, even if you lose part of your erection. Then caress yourself again, stopping and starting several times before you ejaculate. Whether by yourself or with a partner, make sure your erection is as full as can be before you use the strong, rhythmic caresses that bring on your orgasm. Some men learn to ejaculate with a soft penis. However, they find they have stronger orgasms if they can delay orgasm until their erection is as firm as possible.

Special Aspects of Some Cancer Treatments

Urostomy or Colostomy

A urostomy interferes less with your sex life if you make some common-sense changes. First, make sure your appliance fits correctly. Check the seal and empty your ostomy appliance before lovemaking. This will reduce the chance of a major leak. If it does leak, be ready to jump into the shower with your partner and then try, try again. It is also wise to avoid foods like asparagus that give urine a strong odor. Some people now have "continent urostomies" that stay dry without an appliance. With a continent urostomy, a segment of the intestine is cut out and reconnected so the intestines can work normally. From this intestinal tissue, a reservoir and nipple valve/stoma is constructed. The reservoir is connected to the ureters, which prevents backup into the kidneys. Urine is drained from the

reservoir several times a day with a catheter introduced through the stoma/nipple valve. Therefore, there is no need for a bag to collect urine.

A nice pouch cover can make an appliance look less “medical.” Patterns or ready-made covers are available from your entero-stomal therapist or ostomy supply dealer.

Another choice is to wear a special small-sized ostomy pouch during sexual activity. If you have a two-piece system, turn the pouch around on the faceplate. Then the emptying valve is to the side. If you wear an elastic support belt on your faceplate, tuck the empty pouch into the belt during sex. Or you can wear a wide sash around your waist to keep the pouch out of the way. Another way of keeping the pouch from flapping is to tape it to your body. You may also find that you feel more comfortable wearing a T-shirt to cover your appliance.

To reduce rubbing against the appliance, choose positions for sexual activity that keep your partner’s weight off the ostomy. If you have an ostomy but like to be on the bottom during intercourse, try putting a small pillow above your ostomy faceplate. Then, your partner can lie on the pillow rather than on the appliance.

If you have a colostomy, you can do the same thing. Since a colostomy is not active all the time, you may be able to plan sexual activity for a time of day when you know yours is usually not active.

If you irrigate your colostomy, you may be able to wear just a stoma cover or a small safety pouch during sex. You can also avoid eating foods that produce gas on days when you are likely to make love.

Some men and women feel sexual pleasure when their ostomy is touched. If this is true for you, don’t feel that you are abnormal or strange. Remember, though, that a stoma is delicate and can be irritated or even torn by too much rubbing. You should never put an object into your stoma, unless you are following special instructions from your doctor on dilating a stoma.

Laryngectomy

Laryngectomy is the surgery that removes the voice box. It leaves the person without the normal means of speech and you breathe through a stoma in your neck. Since the air you breathe can't be purified by the nose's natural filter, a stoma cover is needed. Besides catching dust and particles, the stoma cover hides the mucus that the stoma secretes. A scarf, ascot tie, or turtleneck shirt can look nice and hide the stoma cover. Even during sexual activity, a stoma cover looks more appealing than a bare stoma.

During sexual activity, a partner may at first be startled by breath that hits at a strange spot. On the positive side, one patient quipped, "Now when I kiss, I never have to come up for air!"

You can lessen odors from the stoma by avoiding garlic or spicy foods, and by wearing cologne or after-shave lotion.

Sometimes problems in speaking interfere with the communication for some couples. If you have learned esophageal speech, talking during lovemaking is not a big problem. It does take more effort, though, and you lose some of the emotional overtones. A speech aid built into the stoma might also work well. However, neither method lets you whisper romantically in your partner's ear.

If you use a hand-held speech aid, communication during sex is likely to be awkward and distracting. You can say a great deal sexually, however, by guiding your partner's hand or using body language.

Talking is not needed in many sexual situations. With a new partner, you may want to discuss the kinds of touching and positions you like before you start making love.

Treatment for Facial Cancers

Some cancers of the head and neck are treated by operations that remove part of the facial bone structure. Because the scars that result are so public, they can be devastating. Surgery on the jaw, palate, or tongue can also disrupt speech.

Recent advances in facial prostheses and in plastic surgery now give many people a more normal look and clearer speech. Even ears and noses can be made out of plastic, tinted to match the skin, and attached to the face. All of these things can be a great help to a person's self-esteem.

There are a number of other things a person can do to improve self-esteem. See the next section, *Keeping Your Sex Life Going*, which includes ideas for coping with changes in appearance. Also, you may wish to contact the organization "Let's Face It." Please see the list of Resources at the end of this booklet.

Limb Amputation

Treatment for some cancers, most often primary tumors of the bone, can include amputating a limb. Amputations may call for some changes in lovemaking. A patient who has lost a limb may wonder, for example, whether to wear his limb prosthesis during sex.

The answer depends on the couple. Sometimes the prosthesis helps with positioning and ease of movement. However, the straps that attach it can get in the way. Without a prosthesis, the partner with an amputation may have trouble staying level during intercourse. Pillows can be used to support the remaining part of the limb.

Amputations may create chronic pain or phantom limb feelings. These side effects can interfere with sexual desire and distract a person during sex. The American Cancer Society offers information about managing pain control.

Loss of One or Both Testicles

Testicles are as symbolic of manhood as breasts are of womanhood. Although some men are not upset about their new appearance, others fear a partner's reaction. This is particularly true of men who are single.

Men treated for prostate cancer that has spread beyond the local area may have both testicles removed to stop production of the hormone (testosterone) that nourishes the cancer. The cords at the top of the testicles remain, however, so the scrotum (sac) does not look empty. After this operation, some men may also have estrogen hormone therapy. To keep breasts from

developing, the doctor will often order a low dose of radiation to the tissue around the nipples before hormone therapy begins. As time goes by, small changes in skin texture or in the shape of a man's body may occur. For example, extra fat may appear on the hips or thighs rather than in a "pot belly." These changes are so minor, however, that most people do not notice them.

In men with testicular cancer, the surgeon usually removes only the abnormal testicle. Only a very few men ever develop a second tumor in the other testicle. Since the operation also removes the cord above the testicle, that side of the scrotum does look and feel empty.

Men with testicular cancer are usually young. They may be single and dating, or they may be athletic and feel embarrassed by the missing testicle when playing sports or in locker-rooms. To restore a more natural look, a man can have a testicular prosthesis surgically implanted in his scrotum. The prosthesis is filled with silicone gel, and it comes in many sizes to match the remaining testicle. When in place, it looks and feels like a testicle. The only evidence left of the operation is the scar, which is often partly hidden by pubic hair.

When part of the scrotal skin must be removed, a testicular prosthesis may not be able to make the scrotum look normal.

Penectomy

When a man has cancer of the penis or of the bottom end of the urethra, the best treatment may be amputation of part or all of the penis. These operations are rare, but they can have a devastating effect on a man's self-image and his sex life. If cancer of the penis is diagnosed early, local radiation or chemotherapy creams can sometimes be used to treat it. These treatments often have little effect on sexual pleasure and function. More commonly, however, the only way to stop the cancer is to remove part or all of the penis.

Partial penectomy removes only the end of the penis. The surgeon leaves enough of the shaft to allow the man to direct his stream of urine away from his body.

Men are usually surprised to learn that a satisfying sex life is possible after partial penectomy. The remaining shaft of the

penis still becomes erect with excitement. It usually gains enough length to achieve penetration. Although the most sensitive area of the penis (the glans or “head”) is gone, a man can still reach orgasm and have normal ejaculation. His partner also can still enjoy intercourse and often reach orgasm.

If the shaft cannot be saved, the man must have a total penectomy. This operation removes the entire penis, including the roots that extend into the pelvis. The surgeon creates a new opening for the urethra (tube from the bladder) between the man’s scrotum (sac for the testicles) and his anus. The man can still control his urination, because the “on-off” valve in the urethra is above the level of the penis.

Some men give up on sex after total penectomy. Since cancer of the penis is most common in elderly men, many have already stopped sexual activity because of other health problems. If a man is willing to put some effort into his sex life, however, pleasure is possible after total penectomy. He can learn to reach orgasm when sensitive areas such as the scrotum, skin behind the scrotum, and the area surrounding the surgical scars are caressed. Having a sexual fantasy or looking at erotic pictures or stories can also increase excitement.

He can help his partner reach orgasm by genital caressing with his fingers, by oral sex, or by stimulation with a vibrator. The activity some couples have after total penectomy can give hope to those coping with lesser changes in their sex lives.

Keeping Your Sex Life Going

In the United States, sex is all too often viewed as something only for the young and healthy. Too often, sexual attractiveness is judged only by a skin-deep sort of beauty rather than according to kindness, maturity, or a sense of humor. Most people, of course, cannot be “a perfect 10.” When people are treated for cancer, their self-esteem often falls to a “1” or “2.”

All people tend to underestimate their physical beauty compared with others’ judgments. After cancer treatment, it is very easy to focus only on the part of the body that has been affected. For example, a man who has had a laryngectomy may fear he will not be able to find another partner because he has lost his voice.

Sometimes friends and lovers do withdraw emotionally from a cancer patient. But when a wife cannot bear to look at her husband’s ostomy appliance, she is often showing deeper feelings. Perhaps she is angry because she has to take over her husband’s usual tasks of paying bills and doing household repairs. His illness may remind her of how devastated she would feel if he died. It is easier not to love him so much. She also may be more aware of her own vulnerability. Yet all these feelings get blamed on a scar that mars one small corner of her husband’s body. The husband, in turn, feels like a sexual failure. Similar conflicts can occur when the female partner in a relationship has had cancer.

Coping with Changes in Appearance

The keys to feeling good about yourself begin with focusing on your best features. Second, try to limit the damage cancer can do to your appearance, your energy, and your sense of well-being. When you are going through cancer treatment, you can feel more attractive by creating a “healthy illusion”—disguising the changes cancer has made and drawing attention to your best points.

The following mirror exercise can help you adjust to any body changes:

- What do you see when you look at yourself in the mirror? Many people notice only what they dislike about their looks. When they look in the mirror, they see a pale complexion, hair loss, an ostomy appliance, or skinny legs. They fail to see a classic profile, strong-looking hands, or a nice smile.
- Find a time when you have privacy for at least 15 minutes. Be sure to take enough time to really think about your appearance. Study yourself for that whole time, using the largest mirror you have. What parts of your body do you look at most? What do you avoid seeing? Can you catch yourself having negative thoughts about the way you look? What are your best features? Has cancer or its treatment changed the way you look?
- First, try the mirror exercise when dressed up. If you normally wear clothing or accessories to disguise changes from cancer therapy, wear them during the mirror exercise. Practice this two or three times, or until you can look in the mirror and see at least three positive things about your looks.
- When you are comfortable seeing yourself as a stranger might see you, try the mirror exercise when dressed as you would like to look for a lover. Keep at least some of your healthy illusion. If you've had an ostomy, for example, wear a bathrobe you like. Look at yourself for a few minutes, repeating the steps in the first mirror exercise. What is most attractive and sexy about you? Pay yourself at least three compliments on how you look.
- Finally, try the mirror exercise in the nude, without disguising any changes made by the cancer. If you have trouble looking at a scar, bare scalp, or an ostomy, take enough time to get used to the area. Most changes are not nearly as ugly as they seem at first. If you feel tense while looking at yourself, take a deep breath and try to let all your muscles relax as you exhale. Don't stop the exercise until you have found three positive features or at least remember the three compliments you paid yourself before.

The mirror exercise may also help you feel more relaxed when your lover looks at you. Ask your lover to tell you some of the things that are enjoyable about the way you look or feel to the

touch. Explain that these positive views will help you feel better about yourself. Remember them when you are feeling unsure.

Changing Negative Thoughts

Your thoughts can make a sexual experience good or bad. Become more aware of what you tell yourself about how sexy you are. You may be setting yourself up for failure with thoughts like, “A man who can’t have erections is no good at all in bed.” Almost all of us put ourselves down as lovers now and then.

Write down the three negative thoughts you have most often about yourself as a lover. Some may be connected to your cancer treatment, but other thoughts may have started years ago.

Now write down a positive thought to counter each negative thought. For example, if you said, “I always climax too quickly during intercourse,” you could substitute the statement, “Even though I climax quickly, I always satisfy my lover through caresses after intercourse.” The next time you are in a sexual situation, use your positive thoughts to override the negative ones you usually have. If you have a favorite feature or talent, this is a good time to indulge yourself a little and play it up.

Coping with Outward Effects of Chemotherapy

The most obvious change in those receiving chemotherapy is the loss of hair. You may also lose weight and muscle mass if you are sick to your stomach and have a poor appetite. You may be noticeably pale, and you may also have a permanent catheter placed in your shoulder or arm.

Some physical changes caused by chemotherapy can be disguised, or at least lessened. If you are just starting chemotherapy, you may want to shop for a wig before your hair begins to fall out. Wigs are warm and not really comfortable, so you may decide to save your wig to wear outside the home or hospital. You can collect many hats or caps for private times. You may decide to wear a hat or cap instead of a wig in public. Many men feel a wig is just too much trouble, especially since it is not easy to find one that looks natural.

It's a good idea for a couple to discuss how each of them feels about wearing a wig or head-covering during lovemaking. There is no right or wrong decision. Men often feel ashamed for caring about being bald. However, it can be just as upsetting for a man to lose his hair during cancer treatment as for a woman.

Disguising weight loss, paleness, and infusion catheters is also a challenge. In general, clothes that fit well look better. Wearing something too tight or too baggy will just draw attention to your weight change. High necks and long sleeves can hide a catheter but may be uncomfortable in the summer. Look for thin fabrics that will be cool while covering you.

Sometimes the changes in your body are so upsetting that you can't relax or think positively. Rather than feel like a failure, take this as a good clue that some counseling from a health care professional would be helpful (see the section on Professional Help).

Overcoming Depression

Staying active is a good way to fight depression and reduce stress. Consult your doctor on the kinds of exercise that are right for you. As long as you don't overdo it, exercise should help you feel vital and healthy. You can also reduce the pain and nausea that some cancer treatments cause by learning skills to help you relax. Many methods of relaxation can be learned from cassette tapes, although training by a mental health professional is probably most effective.

If depression persists, there are medications that can sometimes help to restore interest in sex. What doctors call "clinical depression" has a number of symptoms. These include lack of interest in sex, lack of interest in things that usually give you pleasure, and even not being able to feel pleasure at all. Often these feelings are associated with not being able to sleep, changes in eating habits, fatigue, trouble concentrating, and feelings of worthlessness and hopelessness. Depression can be treated with medication to improve your sleep, appetite,

Staying active is a good way to fight depression and reduce stress.

energy, ability to feel pleasure, and, in turn, your self-esteem and desire for sex. This is something to ask your doctor about.

Some of the newer antidepressants, such as selective serotonin reuptake inhibitors (SSRI's), may cause difficulty achieving orgasm. There are measures that can be taken to improve these potential side effects. If this is something that is distressing for you, talk to your doctor about it.

Rebuilding Self-Esteem

Feeling attractive is just one part of your self-image. Dr. Wendy Schain, a psychologist who counsels men and women who have had cancer, describes self-esteem as a collection of bank accounts.

One account contains the net worth of your physical self—what your body can do and how you look. The second account is your social self—how easily you get along with others and the emotional support you can count on. In the third account is the sum total of your achieving self—what you have done in school, work, and personal and family relationships. The fourth account is for your spiritual self—your religious and moral beliefs and the strength they lend you. During your life you make deposits in your accounts, but when a crisis like cancer arises, you must also make withdrawals. Going through cancer treatment has costs in terms of your physical ability to function, your relations with others, your career goals, and sometimes your faith in the fairness of life. When one of your accounts becomes low in funds, you may need a “loan” from one of the others to balance your account.

Try to be aware of the costs of cancer in your life. Make a special effort to get new deposits for the accounts that remain active. That way, a drain from one area of your self-worth will not bankrupt you entirely. If your cancer treatment has affected your looks, focus on the caring you receive from friends and family who react to you on a deep level of intimacy. If treatment interrupts your work, use some of your energy to enrich your social life or your spiritual life.

Although you may sometimes feel that all your accounts are getting low, a more careful look can show some areas where income is still flowing in.

Good Communication

The most important part in resuming sexual activity with a partner is good communication. Men often react to cancer by withdrawing into themselves. They fear their partner would feel burdened by sharing fear or sadness. Unfortunately, through trying to protect each other, each suffers in silence. No couple gets through cancer diagnosis and treatment without some anxiety. Why not discuss those fears with one another, so that you shoulder the load together rather than separately?

Sexual sharing is one way for a couple to feel close during the stress of an illness. If your partner has been depressed and distant, however, you may fear that a sexual advance comes across as a demand. You can bring up the topic of sex in a healthy assertive way. You shouldn't accuse ("You never touch me anymore!"), or demand ("We simply have to have sex soon. I can't stand the frustration!"). Instead, try to state your feelings positively ("I really miss our sex life. Let's talk about what's getting in the way of our touching.").

Overcoming Anxiety

Many couples believe that sex should always happen on the spur of the moment, with little or no advance planning. If you feel awkward and nervous about trying some sexual touching, however, that perfect moment may never arrive. After an illness, a couple needs to schedule some relaxed time together and start their lovemaking slowly.

Part of the anxiety about resuming sex is caused by the pressure to satisfy your partner. A relaxed way to explore your own capacity to enjoy sex is to begin with self-stimulation. Masturbation is not a necessary step in resuming your sex life, but it can be helpful. By touching your own genitals and even bringing yourself to orgasm, you can find out if cancer treatment has changed your sexual response without having to worry about frustrating your lover.

Although most of us learned as children that masturbation was wrong, or at least something to hide, it is not at all harmful. Most men and women have tried touching their own genitals at some time in their lives. Many people who enjoy good sex

lives with their partners still masturbate sometimes. Men and women in their 70s and 80s often still enjoy self-stimulation.

If you feel at ease with the idea, try stroking not just your genitals, but all of the sensitive areas of your body. Notice the different feelings of pleasure that you can have.

The self-help books listed in the section Resources can help you feel relaxed about masturbation. Later you can teach your partner any new discoveries you make about your body's sensitive zones. Even if cancer treatment has not changed your sexual responses, you may invent some new caresses to enhance your sexual routine.

Resuming Sexual Activity with Your Partner

When you feel ready to try sexual touching with your partner, pick an occasion when you have both time and privacy. You may want to set the scene to be especially relaxed. For example, you could light the room with candles or put on some soft music. Although you may feel a little shy, let your partner know, as clearly and directly as you can, that you would like to experiment with some sexual activity.

You could even “make a date” to have some time alone together. You might say, “I feel ready for sex again, but I’d like to take things slowly. Would you be in the mood tonight to try a little touching? I can’t promise that it will go smoothly, but we can have fun trying.”

It is a good idea for couples to put some limits on their touching the first few times they try sexual activity after cancer treatment. We advise starting with a special session devoted to all-over body touching. Each partner takes a turn touching and being touched. One partner lies face down on the bed, allowing the other partner to touch the entire back, from toes to scalp. After about 15 minutes, the partner lying down turns over so the front of the body can be touched.

While being touched, your job is just to be self-centered and tune in to your own feelings. Don’t worry about your partner’s thoughts or feelings. When you are doing the touching, enjoy the shape and texture of your partner’s body. Try many types of

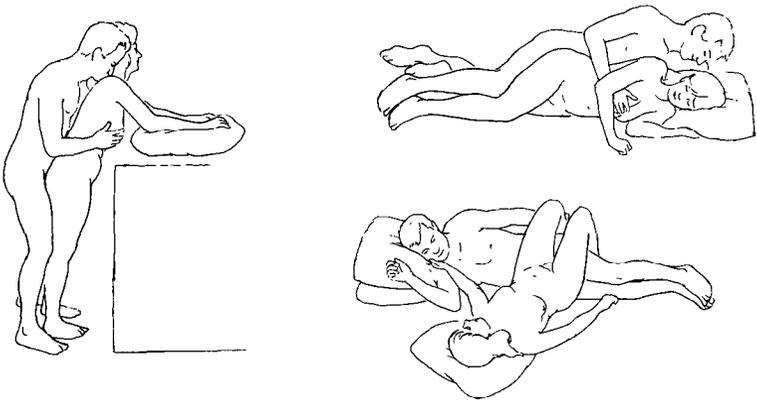
touching, varying light stroking and a firmer touch as in a massage.

The first time you try a touching session, avoid the breasts and genitals. Your goals are to feel relaxed and to feel sensual pleasure. It is not important to get sexually excited. If you agree on these goals before starting, the touching should not be frustrating. This type of session takes the nervousness and pressure out of being close again.

If you both feel relaxed during the first touching session, you can add some genital touching the next time. Over several sessions, partners can slowly spend more time on genital touching, until each one can reach an orgasm through stroking with a hand, or through oral sex, if that is comfortable for both of you.

Many couples don't talk much about sex. After cancer treatment, however, your sexual routine may need to change. This calls for clear communication. This is not the time to let embarrassment silence you. Be sure to let your partner know, either in words or by guiding with your hand, the kinds of touches you like best. Try to express your desires in a positive way. For example, "You have the right place, but I'd like you to use a light touch," rather than, "Ouch! That's too rough!" Delay having intercourse until both partners really feel ready for it.

If cancer treatment has caused an erection problem, intercourse may no longer be possible. Yet a couple can enjoy all the other parts of sex. It would be a shame to give up touching and caressing, just because one aspect of lovemaking has changed.



Making Intercourse More Comfortable

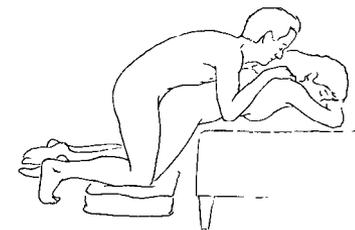
If you still have some pain or feel weak from cancer treatment, you may want to try new lovemaking positions. Many couples have found one favorite position, particularly for intercourse, and rarely, if ever, try another. In our society, probably the most common way to have intercourse is in the “missionary position,” with the man lying on top of the woman.

If a man is feeling weak or out of breath, however, the missionary position may take too much effort. You may be able to enjoy intercourse more if both of you lie side-by-side, either facing each other or with your partner’s back next to your front side.

Another position that may work well is for the woman to sit astride her partner. This allows her to move more freely while her partner relaxes or touches her with his hands.

The drawings on these pages show positions to help in resuming intercourse after cancer treatment.

There is no magic position that is right for everyone. You and your partner need to find the one that is best for you. Small and large pillows can help as supports. Seeing the humor in figuring out the best way to have intercourse can help lighten the process.



Rekindling Sexual Interest

Everyone has a sexual thought or feeling from time to time, but we often ignore or forget about them. If you have not noticed any interest in sex lately, try keeping a "Desire Diary."

Every day for a week prepare a sheet of paper that will become your Desire Diary. Take it with you wherever you go. When you have a sexual thought or feeling, write it down. Note the time of day, whether you were alone or with someone. Also note what you did about the thought. An example of one man's Desire Diary is shown below.

Although the man did not have any sexual activity, he felt desire a few times during the day. Sometimes just keeping track of your desire will increase the number of sexual thoughts and feelings that you notice. You might also find that certain settings or people help you feel more sexual. Perhaps you think about sex most often in the evening, or when you are at work, or in the presence of your partner. Once you have noted some patterns, you can work at putting yourself in the situations that spark a sexual mood.

<i>Monday</i>			
<i>Time</i>	<i>Who was with me?</i>	<i>Sexual thought or feeling</i>	<i>Action taken</i>
<i>7:30 a.m.</i>	<i>Wife</i>	<i>Wanted to caress my wife's breast while she was making breakfast.</i>	<i>None, because I knew she'd be annoyed.</i>
<i>1:30 p.m.</i>	<i>Alone</i>	<i>Noticed a good-looking woman by the coffee machine at work. Wondered what she'd look like without her clothes.</i>	<i>None</i>
<i>3:15 p.m.</i>	<i>Alone</i>	<i>Thought about making love tonight.</i>	<i>None</i>
<i>10:00 p.m.</i>	<i>Wife</i>	<i>Felt turned-on when I got into bed.</i>	<i>Asked her if she wanted to have sex. She said she was too tired, but maybe in the morning.</i>

Some people feel more sexual if they get some exercise, if they plan a relaxed evening out with their partner, or if they make special efforts to look and feel sexy. Think about the things that have helped to get you into a sexy mood before. Try looking at erotic pictures, reading a story steamy with sex, or watching a movie with a romantic or sexual plot. Fantasize about a sexual encounter. Picture it as you would like it to be. How can you make your daydream come true?

Although you can work at feeling more sexual by yourself, you will want to get your partner's help at some point. Discuss any fears either of you has about resuming sex. If you have questions about medical risks, you and your partner should discuss them with your doctor.

If these efforts to spark your sexual interest fail, think about seeking some sexual counseling. The section Professional Help offers ideas.

The Single Man with Cancer

Getting through cancer treatment can be really tough emotionally for a single man. You may not have a friend or family member whom you can trust as you would a spouse. Perhaps you also worry that a current or future lover will reject you because you've had cancer.

Some of the scars left by cancer are public, such as the loss of hair during chemotherapy, the loss of a limb, or a facial disfigurement. Other scars will not be seen by a casual onlooker. For example, nobody would guess that a man on the street had had a colostomy. These private scars can be just as painful, however, since the few people who do see them are the ones whose acceptance matters most.

Perhaps the most private scar left by cancer is the damage done to your view of yourself. You may not be feeling healthy and whole, with an unlimited future. You may be wondering about how active you can be and even how long you will live. If you had hoped to marry or to remarry, you may not want to

involve a lover in such a shaky future. Homosexual relationships have the same worries too.

Concerns about having children can also affect your new relationships. Perhaps you have lost your fertility because of cancer treatment. Maybe you can still have children, but fear that cancer will not give you time to see your child grow up.

In dating relationships, men or women who have had cancer often avoid talking about their illness. At a time when closeness and companionship are so important, it can seem risky to draw a lover's attention to your problems. During treatment, you want to appear brave and not complain. Even after the cancer has been controlled, you may try to forget that the illness ever took place.

Sometimes you can ignore the cancer. However, when a relationship becomes serious, silence is not the best plan. Before partners decide to make a strong commitment, such as marriage, they should discuss the cancer. This is true especially if life expectancy or fertility has been affected. Otherwise, cancer may become the "skeleton in the closet," a secret that will limit your ability to confide in your partner. A loving partner needs to accept you as you are.

When to Talk about Your Cancer

Ideally, a couple should discuss cancer when a relationship begins to deepen, rather than on the eve of the wedding. Try having a talk when you and your partner are relaxed and in an intimate mood. You can ask your partner a question that leaves room for many answers. An example is, "You know that I had leukemia several years ago. How do you think that might affect our relationship?" You can also reveal your own feelings: "I guess I hesitate to bring up my treatment for cancer because I'm afraid you'd rather be with someone who has not had the disease. It also scares me to remember that time of my life. But

Sometimes you can ignore the cancer. However, when a relationship becomes serious, silence is not the best plan.

I really want to know if you have any worries about my having cancer.”

If you have an ostomy, genital scars, or a sexual problem, you have a special dilemma. When should you tell a new dating partner about your hidden problem? No hard and fast rules exist. During the first few minutes after meeting is certainly too soon. On the other hand, if you wait until you are about to get into bed together, you are courting disaster. It is better to wait until you feel a sense of trust and friendship with your partner—a feeling that you are liked as a total person.

The Possibility of Rejection

The sad truth is that some potential lovers may reject you because of your cancer treatment. Of course, almost everyone gets rejected sometimes. Even without cancer, people reject each other because of looks, beliefs, personality, or their own circumstances. The tragedy is that some single people with cancer limit themselves by not even trying to date. Instead of focusing on their good points, they convince themselves that no partner would accept them because of the cancer and the effects of treatment. Although you can avoid being rejected by staying at home, you also miss the chance to build a happy relationship.

Improving Your Social Life

Try working on areas of your social life other than dating and sex. Single people can avoid feeling alone by building a network of close friends, casual friends, and family. Make the effort to call friends and plan visits or shared activities. Get involved in a hobby, special interest group, or adult education course that will increase your social circle. Some volunteer and support groups are geared for people who have faced cancer (see Resources at the end of this booklet).

You may also want to try some individual or group counseling with a mental health professional. You can take a more positive view of yourself when you get objective feedback about your strengths from others. Make a list of your good points as a mate. What do you like about your looks? What are the good points in your personality? What are your talents and skills? What can you give to your partner in a relationship? What

makes you a good sexual partner? Whenever you catch yourself using cancer as an excuse not to date, remind yourself of your assets.

If you feel shy about meeting new people, practice how to handle it. Talk to yourself in the mirror, or ask a close friend or family member to role-play with you.

You can even rehearse how to tell a dating partner about your experience with cancer. What message do you really want to give? Try some different ways of saying it, and ask a friend for feedback. Did you come across as intended? Ask your friend to take the role of a new partner who rejects you because you have had cancer. Have your friend tell you what you dread hearing the most, and practice your response. Can you express your feelings in a dignified and satisfying way?

When you feel some confidence in your self-worth and your ability to handle rejection, you are ready for the real world. Then, when you start to meet people or to date, think of it as part of a learning process rather than a situation demanding instant success.

Dispelling Myths About Cancer

Can Sexual Activity Cause Cancer?

Usually, no. Because sexuality has sometimes been seen as “sinful,” people worry that sexual activity has caused their cancer. Such fears are common if the cancer starts in an area of the body regarded as sexual, such as the penis, prostate, cervix, or breast. For most cancers, however, there is no link between a person’s sex life and the risk of developing a tumor. Nor does resuming sex after cancer treatment increase the chances of cancer coming back or getting out of control.

A few kinds of cancer may be caused by a virus that is passed from one person to another through sexual contact. These cancers are not caused by having sex itself, but by the virus. They include squamous cell carcinoma of the cervix, vulva, penis, or rectum. They also include Kaposi’s sarcoma or other

cancers in people with acquired immunodeficiency syndrome (AIDS).

For cancer of the cervix, vulva, penis, or rectum, the viruses most under suspicion, are the herpes II virus, which causes genital herpes; the cytomegalovirus, which causes a special kind of herpes; and especially the human papillomavirus, which causes genital warts. The roles of these viruses are not fully understood. Most people who get the viruses never develop cancer. Also some people with cancer of the cervix or vulva show no signs of ever having had one of the viruses. The viruses are probably not the only causes of these cancers. Some people may be more likely to get the virus because of their age, poor health, heredity, or past experience with other cancer-causing agents.

Women who smoke cigarettes, for example, have an increased risk of cervical cancer. Women who become sexually active before age 18 also seem at higher risk for cancer of the cervix. Men who are not circumcised have a greater tendency to develop cancer of the penis.

If you have had one of these cancers, you may feel a sense of guilt or regret about your past sex life. Such feelings are natural, but they don't help you to deal with cancer. Many of us may have had a sexual encounter that did not conform to our society's ideas of what is "normal." Yet most people who have had the same experiences did not develop cancer. You and your partner should keep in mind that many people with cancer of the cervix, penis, or vulva, or even AIDS-related cancers have had only one lifetime sexual partner. A diagnosis of cancer is not cause to suspect unfaithfulness.

Is Cancer Contagious through Sexual Contact? What about AIDS?

Cancer cannot be passed from one person to another, even through a contact as close as kissing, intercourse, or oral-genital sex.

AIDS, however, is passed to someone by an exchange of body fluids through oral, vaginal, and anal sex. The human immunodeficiency virus (HIV) causes AIDS. This virus is passed on by sexual contact, by sharing an infected person's needle during intravenous drug use, or from a mother to her baby during

pregnancy or breastfeeding. In rare cases, the virus can be passed on by other contacts with an infected person's blood, such as during a blood transfusion or during medical treatment. Unless you know for sure that neither you nor your partner carries the AIDS virus, you should practice safe sex. The safest sex is mutual genital-hand touching. Oral sex can be made safer if you wear a condom or if you use an "oral dam," a rubber sheet that fits over the woman's vulva, during oral sex. A partner should never taste or swallow a man's semen if he might have the HIV virus. Between partners who are not sure whether they carry the HIV virus, vaginal intercourse and anal intercourse can be made safer if you wear a condom. However, this is still not 100% safe.

Many patients and their partners worry that cancer is catching. News stories about viruses and cancer can also be confusing. Contrary to the myths, a cancer cell from one person's body simply cannot take root and grow in someone else. Not only are all cells fragile, needing the proper setting to survive, but the partner's immune system knows the cancer cell is a foreigner and destroys it. Cancer itself is not contagious.

Can Sex Be Harmful to a Patient or Partner?

Some people with cancer stop having sex because they fear that it will make the cancer worse. Sometimes the worries are vague, coming from the image of sex and cancer as both somehow unclean. A few people believe that cancer is a punishment for past sins. They try to "bargain" with God, promising to give up sex in return for a cancer cure. If you have had such thoughts, a talk with your minister, priest, or rabbi may be comforting. Few religions support such a harsh view of illness. From a scientific point of view, there is no reason for sex to cause a cancer to return.

Although sexual activity is usually safe during and after cancer treatment, some couples stop all sex for no reason, without checking out their fears with the health care team. If you have been cleared medically to resume sex, but are still unsure, perhaps you just need more time. Keep monitoring your feelings. Are there times when you feel a stirring of sexual desire?

You may also need to reassure your partner that your cancer treatment does not make sexual activity dangerous. Cancer is not contagious.

Be sure to let your partner know that you will want to have sex as soon as you feel better. Give your partner some ideas on helping you feel more sexual again, such as, “Try being affectionate in a relaxed way,” “Let me know that you still find me attractive.” You may also need to reassure your partner that your cancer treatment does not make sexual activity dangerous. Cancer is not contagious. Having sex does not expose your partner to radiation during sexual activity with you. A few chemotherapy drugs can be present in small amounts in semen or vaginal fluids. Ask your doctor whether you should use condoms just around the time of receiving your chemotherapy.

When Should a Person with Cancer Not Have Sex?

If you are wondering whether sexual activity would cause a problem with treatment, the first rule is to ask your doctor’s opinion. Each cancer patient must be treated individually. There are, however, some basic guidelines.

For most persons with cancer, having sex is not harmful. Sometimes, however, sex can be hazardous. During recovery from surgery intercourse can cause bleeding or strain the incision. Intimate contact may also increase chances of an infection. The time between surgery and resuming your sex life varies. This depends on the type of operation and your rate of healing. Your surgeon can tell you when it would be safe to try sexual activity again.

Some types of cancer, like cancer of the cervix or bladder, may cause bleeding in the genital area or urinary tract. If this bleeding becomes heavier after sex, it is wiser to cease intercourse until cancer treatment stops the bleeding.

During chemotherapy, a person with an infusion catheter sometimes worries that sexual activity will disturb it. As long as you take care not to rub against the dressing, sexual activity should not be a problem.

A person receiving cancer treatment often has times when the immune system is not working as well as it should. This may happen during radiotherapy or chemotherapy. At such times, it is easier for you to get all kinds of infections. Again, ask your doctor for advice on whether sexual contact poses too much threat of infection, which can include sexually transmitted diseases (STDs) such as genital herpes, gonorrhea, chlamydia, and the HIV virus. Talk with your doctor about your risk of getting an STD and how you can protect yourself. Most doctors say that if you are well enough to be out in public, you are well enough to have sex. If you are in the hospital because of weak immunity, ask your doctor's advice on kissing, cuddling, or sexual touching.

Bacteria that can start infections in the urinary tract or genital area may wash away if you urinate a few minutes after sex. You might want to drink a glass of water before you make love, so it will be easier to urinate.

If you notice any strange sore on your partner's penis, or a whitish fluid (other than semen) in the opening at the tip, you should ask for an explanation of the symptom before having sex. STDs are harder to spot in a woman. However, a man might gently ask whether his lover has had any recent signs of an STD, for example, vaginal discharge, painful urination, or a bump, sore, or blister in the genital area.

Remember that STDs like the HIV virus or chlamydia usually do not leave visible signs. Often the person with an STD does not know he or she has it. You can reduce your chances of getting an STD if you wear a condom. The sperm-killing chemicals in contraceptives also seem to fight bacteria and some viruses. If chemotherapy irritates a woman's vagina, however, foams or jellies may make the problem worse.

Others' Views of Cancer

Even if a cancer treatment has not left obvious scars, many people still take the outdated view that having cancer carries a stigma. They feel that the person with cancer may be unclean or somehow to blame for the disease. These ideas have no basis in fact. Feelings of guilt or blame can only detract from the efforts you make toward solving sexual problems.

Advanced Cancer

People who know little about cancer also assume it is always fatal. A very ill person is not often seen as a sexual person, although sexual feelings exist in everyone, even in times of very poor health. In a nation where one out of every two to three people will have cancer in his or her lifetime, and where survival rates are steadily going up for those with cancer, these beliefs are unfounded and harmful.

Some men and women lose hope and stop trying to fight the cancer because they have lost intimacy in their lives. When cancer is far advanced, a person's needs for affection, sharing of feelings, and touch may become even stronger. Partners of patients can help by remembering the importance of physical closeness, even when intercourse might be too much for the person with cancer.

Professional Help

The first step in finding help for a sexual problem is to discuss it with your doctor. Ideally, he or she can suggest a specialist in sexual problems.

Many health care professionals, including doctors, have little training in sexuality problems. They may not be at ease even talking about sex. Doctors may fail to mention the sexual side effects of cancer or of medical treatments. Also they may provide such a sketchy picture that you may conclude that your sex life is over. If your cancer specialist can't help you, we suggest you ask your family doctor, or other members of your health care team. If your doctors cannot give you a referral, a number of different programs and specialists often help. These include:

Sexual Rehabilitation Programs in Cancer Centers

A center that specializes in treating cancer may have experts on its staff who can evaluate and treat a sexual problem. However, often these specialists see only patients who are being treated for cancer at their hospital. If you are getting treatment at a cancer center, check to see what programs are offered.

Sexual Dysfunction Clinic Staffs

In recent years, medical schools and even private practice groups have been opening comprehensive clinics to treat sexual problems. Such clinics often provide both psychological and medical exams and treatments. The clinic staff may include psychologists, psychiatrists, social workers, urologists, gynecologists, endocrinologists, or specialists who run a sleep laboratory. Some clinics require both sexual partners to participate in the evaluation, though you may be seen alone if you are not in a committed relationship. Some clinics offer a more complete range of services than others. You can also call the nearest medical school and ask if they have a sexual dysfunction clinic.

Sex Therapists

Sex therapy is a brief type of psychotherapy (usually 10 to 20 sessions) focused on solving a sexual problem. Sex therapists believe that a person learns lovemaking skills and that bad habits can be corrected by learning sexual techniques. In between meetings with the therapist, a couple (or sometimes just a man or woman treated alone) is given “homework” assignments. The homework consists of exercises to develop better communication and more enjoyment of touching. It also reduces anxiety that interferes with good sex.

Sex therapists may practice in the clinic or independently. Because most states have no laws regulating the title “sex therapist,” a person with no formal training can often call herself or himself a sex therapist. A sex therapist should, however, be a mental health professional (psychiatrist, social worker, psychiatric clinical nurse specialist or nurse practitioner, or psychologist) with special training in treating sexual problems with sex therapy. Some counselors may provide sexual counseling if a licensed professional supervises them.

It is not always easy to find a well-trained sex therapist. It is even harder if you live far from a city. Professional societies such as the American Association of Sex Educators, Counselors, and Therapists (AASECT) can give you information about their members who have specific training in sex therapy. You can also get a listing of sex therapists that practice in your area by contacting your state’s psychological

Sex therapy is not the only kind of counseling that can be helpful to a person with cancer.

association, or chapter office for the National Association of Social Workers, or state association for licensed Marriage and Family Therapists.

Other Kinds of Counseling

Sex therapy is not the only kind of counseling that can be helpful to a person with cancer. Psychotherapy can allow you to feel better about the changes in your body, help you improve communication in your relationship, or give you skills to cope more easily with the cancer.

Finding a well-qualified mental health professional is important. A psychiatrist has an MD (Doctor of Medicine) degree and has usually completed a hospital residency in psychiatry. He or she should also be certified by the American Board of Psychiatry and Neurology.

Most psychologists practicing independently have a PhD (Doctor of Philosophy) degree, or sometimes a PsyD (Doctor of Psychology) or EdD (Doctor of Education). In most states a psychologist must be licensed. Those who practice usually have a degree in clinical or counseling psychology.

Social workers usually have a master's degree in social work (MSW). Again, licensing laws vary from state to state. Some states have a category for licensed psychotherapists called marriage and family counselors. They usually have master's degrees in psychology or a related field, plus training in counseling.

Psychiatric clinical nurse specialists or psychiatric nurse practitioners have a master's degree in psychiatric nursing. They are licensed professionally, but their ability to practice independently also varies state to state.

The expense of counseling varies with the professional's training. One way to get quality treatment for a lower fee is to find a nearby medical school with a psychiatry clinic. You can also go to a university that trains clinical psychologists and has a

psychology clinic. A student in advanced training will see you, but she or he will be supervised by a senior professional.

Other Medical Specialists

A man with sexual problems may choose to consult a urologist, a physician specializing in diseases of the genitals and urinary tract. Many urologists perform surgery or prescribe medical treatments for erection problems. They have the special examination equipment needed to find the cause of an erection problem.

When the most likely cause for a sexual problem is a hormone imbalance, an endocrinologist can be consulted. Endocrinologists are expert in the complex cycles and systems that control hormone levels. Usually, your primary doctor is best able to decide whether the special knowledge of an endocrinologist is needed to solve your problem.

What to Avoid

Unfortunately, men and women seeking help for a sexual problem often go to someone who is not really a health care professional. Since sexual problems are so common and so upsetting, many unproven remedies are available. Although there is no evidence that any of the following can cure a sexual problem, they are often said to be cures: potency pills, such as “poppers” or “Spanish fly,” oysters, rings or rubber bands around the base of the penis, “splints” that fit around the outside of the penis to stiffen it, muscle exercises that claim to enlarge a man’s penis, hypnotism by someone not trained as a mental health professional, or visits to an independent “sexual surrogate.” Pursuing such useless treatments not only wastes your time and money but can sometimes be harmful.

Looking Ahead

Sexuality is an important part of everyday life. We hope this booklet will help to enrich your days, enabling you and your partner to remain as close to each other as possible.

Resources

Books

Bostwick, David G., Gregory T. MacLennan, and Thayne R. Larson. *Prostate Cancer: What Every Man—And His Family—Needs to Know* (Revised). New York: Villard Books, 1999.

Korda, Michael. *Man to Man: Surviving Prostate Cancer*. New York: Vintage Books, 1997.

Schover, Leslie R. *Sexuality and Fertility After Cancer*. New York: John Wiley & Sons, 1997.

Zilbergeld, Bernie. *The New Male Sexuality: The Truth About Men, Sex, and Pleasure*. New York: Bantam Books, 1999.

Related Publications

From the American Cancer Society. Single copies are free and available from the American Cancer Society. Call 1-800-ACS-2345 and ask about the following titles:

Cancer Facts for Men (2008; Spanish 2624)

Prostate Cancer Essay (CID document)

Sexuality and Cancer: For the Woman who Has Cancer and Her Partner (4657)

Testicular Cancer Essay (CID document)

From the National Cancer Institute, Call 1-800-4-CANCER to request booklets (no charge):

Facing Forward: A Guide for Cancer Survivors

What You Need to Know About Prostate Cancer

Questions and Answers About Testicular Cancer

From the United Ostomy Association, Inc., Call 1-800-826-0826, or visit their Web site (www.uoa.org) to order:

Colostomy—A Guide

Gay and Lesbian Ostomates and Their Caregivers

Ileostomy—A Guide

Sex and the Female Ostomate

Sex and the Male Ostomate

Sex, Courtship and the Single Ostomate

Urostomy—A Guide

Educational Videotapes on Cancer and Sexuality

From Leo Media Inc., Call (217) 377-0700 or visit their Web site (www.leomed.com) to view the health-related videotape library:

Controlling the Behavioral Side Effects of Chemotherapy. Burish, Thomas, and Redd, William. A 20-minute video on relaxation techniques to control symptoms of chemotherapy.

Relaxation Audiotapes

Visualization for Treating Cancer. Fanning, Patrick. 1992. \$11.95, New Harbinger Publications, Inc., www.newharbinger.com, 1-800-748-6273.

Transforming Your Chronic Pain. Kane, Jeff. 1992, \$11.95. New Harbinger Publications, Inc., www.newharbinger.com, 1-800-748-6273.

Relaxation Procedures in Cancer Treatment. I. Passive Relaxation (W. Redd) II. Active Relaxation (T. Burish). \$25 for 2, 30-minute audiocassettes. LeoMedia Inc., www.leomed.com, (217) 337-0700.

Time Out From Stress, Volumes 1 and 2. (Visualization, muscle relaxation, deep breathing, with music). 1993 and 1994. \$11.95 each. New Harbinger Publications, Inc., www.newharbinger.com, 1-800-748-6273.

Support and Service Organizations

To obtain the current addresses, phone numbers, and/or web sites of the organizations listed below, or to find other available resources, please call the American Cancer Society at 1-800-ACS-2345.

International Association of Laryngectomees (IAL).

Members of this network of 300 clubs have had their larynx (voice box) removed, usually because of cancer. The IAL provides skills education for laryngectomees, and works toward the total rehabilitation of the patient. They maintain a registry of post-laryngectomy speech instructors, and sponsor an annual meeting, annual Voice Rehabilitation Institute, and other activities.

Let's Face It, Inc. A national support network for people with facial disfigurement. Publishes an annual 60-page resource list.

Leukemia & Lymphoma Society of America, Inc. Patient service programs and resources available through local chapters of the Leukemia & Lymphoma Society include financial assistance, support groups, one-to-one volunteer visitors (in some chapters), patient education and information, and referral to local resources in the community.

National Cancer Institute. The National Cancer Institute (NCI) is the US government's main agency for cancer research, training, and information dissemination. NCI provides information on cancer research, diagnosis, treatments, comprehensive cancer centers, clinical trials, and community clinical oncology programs.

National Coalition for Cancer Survivorship (NCCS).

Provides peer support and distributes information to help patients and families deal with the issues of survivorship. Network of individual, institutional, and organizations working in the area of cancer support, advocacy, and survivorship. NCCS serves as a clearinghouse of information on support groups and provides advice on health insurance issues and employment rights for survivors. Offers free publications and publishes a quarterly newsletter.

United Ostomy Association, Inc. (UOA). The UOA sponsors local Ostomy Association chapters, with monthly meetings and a visitors program.

US TOO International. A non-profit, international organization of support groups for the purpose of fellowship, counseling, and discussion of current medical alternatives and options for men with prostate cancer and their families.

Computer-Based Resources

Note: Since the Internet is growing rapidly, web addresses change frequently. Lists of sites on the World Wide Web are often out of date as soon as they appear in print. To find the most recent location, use a search engine such as Yahoo or Alta Vista.

American Association of Sex Educators, Counselors, and Therapists (AASECT)
<http://www.aasect.org>

American Cancer Society
<http://www.cancer.org>

CancerNet (National Cancer Institute)
<http://cancernet.nci.nih.gov>

Oncolink
<http://www.oncolink.com>

American Cancer Society

The American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy, and service. The American Cancer Society offers up-to-date cancer information, educational programs, services, and referrals.

Check your local telephone directory for your nearest American Cancer Society office or call 1-800-ACS-2345. The following programs may be available in your community:

I Can Cope

This program addresses the educational and psychological needs of people with cancer and their families. A series of classes discusses the disease, coping with daily health problems, expressing feelings, living with limitations, and local resources. Through lectures, group discussions, and study

assignments, the course helps people with cancer regain a sense of control over their lives.

Man to Man

The Man to Man Education and Support Program of the American Cancer Society is specially designed for men and their families who have prostate cancer concerns. The purpose of the program is to provide accurate information about diagnosis, treatment options, living with side effects of treatment, and other related issues in a supportive atmosphere. Men and their partners are able to ask questions and share common experiences and feelings with the assistance of qualified health professionals and the mutual aid of the group. This program also promotes awareness of prostate cancer as a major health care concern for all men. It is believed that men and their partners can greatly benefit from the program and that participation immediately following diagnosis is especially important to help reduce anxiety and facilitate a healthy adjustment. There is also a Man to Man Bulletin Board on the American Cancer Society web site where men can get answers to questions about prostate cancer. Expert Answers for Prostate Cancer allows users to view questions and answers as well as post their own medical questions.

©2001, American Cancer Society, Inc.
99-Rev. 01/01-25M-No. 4568-HCP



1.800.ACS.2345
www.cancer.org

Hope.Progress.Answers.

Managing Cancer Pain

Patient Guide

Management of Cancer Pain



Consumer Version
Clinical Practice Guideline
Number 9

Facts About Cancer Pain Treatment

If you are being treated for cancer pain, you may have concerns about your medicine or other treatments. Here are some common concerns people have and the facts about them.

Concern: I can only take medicine or other treatments when I have pain.

Fact: You should not wait until the pain becomes severe to take your medicine. Pain is easier to control when it is mild than when it is severe. You should take your pain medicine regularly and as your doctors and nurses tells you. This may mean taking it on a regular schedule and around-the-clock. You can also use the other treatments, such as relaxation and breathing exercises, hot and cold packs (see pages 8 and 17), as often as you want to.

Concern: I will become “hooked” or “addicted” to pain medicine.

Fact: Studies show that getting “hooked” or “addicted” to pain medicine is very rare. Remember, it is important to take pain medicine regularly to keep the pain under control.

Concern: If I take too much medicine, it will stop working.

Fact: The medicine will not stop working. But sometimes your body will get used to the medicine. This is called tolerance. Tolerance is not usually a problem with cancer pain treatment because the amount of medicine can be changed or other medicines can be added. Cancer pain can be relieved, so don't deny yourself pain relief now.

Concern: If I complain too much, I am not being a good patient.

Fact: Controlling your pain is an important part of your care. Tell your doctor or nurse if you have pain, if your pain is getting worse, or if you are taking pain medicine and it is not working. They can help you to get relief from your pain.

You may have concerns about your treatment that were not discussed here. Talk to your doctor or nurse about your concerns.

Managing Cancer Pain

Purpose of This Booklet

This booklet is about cancer pain and how it can be controlled. Not everyone with cancer has pain. But those who do can feel better with proper pain treatment.

Reading this booklet should help you to:

- Learn why pain control is important to you.
- Work with your doctors and nurses to find the best method to control your pain.
- Talk to your doctors and nurses about your pain and how well the treatment is working for you.

Why Pain Should Be Treated

Pain can affect you in many ways. It can keep you from being active, from sleeping well, from enjoying family and friends, and from eating. Pain can also make you feel afraid or depressed.

When you are in pain or uncomfortable, your family and friends may worry about you.

With treatment, most cancer pain can be controlled. When there is less pain, you will probably feel more active and interested in doing things you enjoy.

If you have cancer and you are feeling pain, you need to tell your doctors and nurses right away. Getting help for your pain early on can make pain treatment more effective.

What Causes Cancer Pain?

There are many causes of cancer pain. Most of the pain of cancer comes when a tumor presses on bone, nerves, or body organs. Cancer treatment can cause pain, too.

You may also have pain that has nothing to do with your illness or its treatment. Like everyone else, you can get headaches, muscle strains, and other aches and pains. Because you may be taking medicine for cancer treatment or pain, check with your doctors and nurses on what to take for these everyday aches and pains.

Other conditions, such as arthritis, can cause pain, too. Pain from these other conditions can be treated along with cancer pain. Again, talk to your doctors and nurses about your medical history. They will be able to tell you how each condition can be treated and what is best for you.

Treating Cancer Pain

Cancer pain is usually treated with medicine. But surgery, radiation therapy, and other treatments can be used along with medicine to give even more pain relief (these treatments are listed on page 8). Ask your doctors and nurses how the other treatments can help you.

Choosing the Right Medicine

Pain treatments work differently for different people. Even when a doctor or nurse uses the right medicines and treatments in the right way, you may not get the pain relief you need. While you are being treated for your pain, tell your doctors and nurses how you feel and if the treatments help. The information you give them will help them to help you get the best pain relief.

Your doctors and nurses will work to find the right pain medicine and treatments for you. You can help by talking with them about:

- Pain medicines you have taken in the past and how well they have worked for you.
- Medicines and other treatments (including health foods, vitamins, and other “nonmedical” treatments) you are taking now. Your doctors and nurses need to know about other treatments you are trying and other medicines you take. This is important because some treatments and medicines do not work well together. **Your doctors and nurses can find medicines that can be taken together.**
- Allergies that you have, including allergies to medicines.
- Fears and concerns that you have about the medicine or the treatment. Talk to your doctors and nurses about your fears and concerns. They can answer your questions and help you to understand your pain treatment.

Types of Pain Medicine

Many medicines are used to treat cancer pain, and your doctor may give you one or more of them to take. The list below describes the different types of medicine that you may be taking and the kind of pain they work on. Ask your doctor or nurse to tell you more about the medicine you are taking.

Do not start to take a new medicine without checking with your doctor or nurse first. Even aspirin can be a problem in some people who are taking other medicines or having cancer treatment.

■ For mild to moderate pain—

Nonopioids: Acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs), such as aspirin and ibuprofen. You can buy many of these over-the-counter (without a prescription). Others need a prescription.

■ For moderate to severe pain—

Opioids: Morphine, hydromorphone, oxycodone, and codeine. A prescription is needed for these medicines. Nonopioids may be used along with opioids for moderate to severe pain.

■ For tingling and burning pain—

Antidepressants: Amitriptyline, imipramine, doxepin, trazodone. A prescription is needed for these medicines. Taking an antidepressant does not mean that you are depressed or have a mental illness.

Anticonvulsants: Carbamazepine and phenytoin. A prescription is needed for these medicines. Taking an anticonvulsant does not mean that you are going to have convulsions.

■ For pain caused by swelling—

Steroids: Prednisone, dexamethasone. A prescription is needed for these medicines.

(For more information on pain medicines, see pages 14-15).

About Side Effects

All medicines can have some side effects, but not all people get them. Some people have different side effects than others. Most side effects happen in the first few hours of treatment and gradually go away. Some of the most common side effects of pain medicines are:

- **Constipation** (not being able to have a bowel movement). The best way to prevent constipation is to drink lots of water, juice, and other liquids, and to eat more fruits and vegetables. Exercise also helps to prevent constipation. Your doctors and nurses may also be able to give you a stool softener or a laxative.
- **Nausea and vomiting.** When this happens, it usually only lasts for the first day or two after starting a medicine. Tell your doctors and nurses about any nausea or vomiting. They can give you medicine to stop these side effects.
- **Sleepiness.** Some people who take opioids feel drowsy or sleepy when they first take the medicine. This usually does not last too long. Talk to your doctor or nurse if this is a problem for you.
- **Slowed breathing.** This sometimes happens when the dose of medicine is increased. Your doctor or nurse can tell you what to watch for and when to report slowed breathing.

More serious side effects of pain medicines are rare. As with the more common side effects, they usually happen in the first few hours of treatment. They include trouble breathing, dizziness, and rashes. If you have any of these side effects, you should call your doctor or nurse right away.

How Pain Medicine is Taken

Most pain medicine is taken by mouth (orally). Oral medicines are easy to take and usually cost less than other kinds of medicine. Most oral medicines are in tablet form, but sometimes they are liquids that you drink. If it is hard for you to swallow and you cannot take a tablet or liquid for some other reason, there are other ways to get these medicines. These include:

- **Rectal suppositories** (medicine that dissolves in the rectum and is absorbed by the body).
- **Patches that are filled with medicine and placed on the skin** (transdermal patches).
- **Injections.** There are many kinds of injections to give pain relief. Most injections use a tube or needle to place medicine directly into the body. These include:

Subcutaneous injection—medicine is placed just under the skin using a small needle.

Intravenous injection—medicine is placed directly into the vein through a needle that stays in the vein.

Epidural or intrathecal injections—medicine is placed directly into the back using a small tube.

Most of these injections give pain relief that lasts for many hours.

Subdermal and intramuscular injections— commonly known as “shots,” are injections that are placed more deeply into the skin or muscle using a needle. These injections are not recommended for long-term cancer pain treatment. Constantly having shots into the skin and muscle can be painful. Also, shots take longer to work, and you have to wait for them.

When To Take Your Pain Medicine

To help your pain medicine work best:

- Take your medicine on a regular schedule (by the clock). Taking medicine regularly and as your doctor tells you will help to keep pain under control. Do not skip a dose of medicine or wait for the pain to get worse before taking your medicine.
- Ask your doctor or nurse how and when to take extra medicine. If some activities make your pain worse (for example, riding in a car), you may need to take extra doses of pain medicines before these activities. The goal is to PREVENT the pain. Once you feel the pain, it is harder to get it under control.

Treating pain is important, and there are many medicines and treatments that can be used. If one medicine or treatment does not work, there is another one that can be tried. Also, if a schedule or way that you are taking the medicine does not work for you, changes can be made. Talk to your doctor or nurse because they can work with you to find the pain medicine that will help you the most.

It may be helpful for you to keep a record of how the medicine is working. Keeping a record like the one on pages 18-19 and sharing it with your doctor or nurse will help to make your treatment more effective.

Other Treatments

Your doctor or nurse may recommend that you try other treatments along with your medicine to give you even more pain relief. Relaxation exercises (see page 17) help reduce pain. Many people find that cold packs, heating pads, massage, and rest help to relieve pain. Music or television may distract you from the pain. Your family members may want to help you to use these treatments. These treatments will help to make your medicines work better and relieve other symptoms, but they should not be used instead of your medicine.

Nondrug Treatments of Pain

Here are a few examples of treatments that can help to relieve your pain. You may use these treatments along with your regular medicine:

- Biofeedback.
- Breathing and relaxation.
- Imagery.
- Massage, pressure, vibration.
- Transcutaneous electrical nerve stimulation (TENS).
- Distraction.
- Hot or cold packs.
- Rest.

Talk to your doctors and nurses about these treatments. They will be able to give you more information. Also, the counseling and support groups listed on page 16 may be able to tell you more.

When Medicine Is Not Enough

Some patients have pain that is not relieved by medicine. In these cases other treatments can be used to reduce pain:

- **Radiation therapy.** This treatment reduces pain by shrinking a tumor. A single dose of radiation may be effective for some people.
- **Nerve blocks.** Pain medicine is injected directly around a nerve or into the spine to block the pain.
- **Neurosurgery.** In this treatment pain nerves (usually in the spinal cord) are cut to relieve the pain.
- **Surgery.** When a tumor is pressing on nerves or other body parts, operations to remove all or part of the tumor can relieve pain.

Talk to your doctor about other pain treatments that will work for you.

The First Step

The key to getting the best pain relief is talking with your doctors and nurses about your pain. They will want to know how much pain you feel, where it is, and what it feels like. Answering the questions below may help you describe your pain. You may wish to write your answers in the space after each question.

Where is the pain? You may have pain in more than one place. Be sure to list all of the painful areas.

What does the pain feel like? Does it Ache? Throb? Burn? Tingle? You may wish to use other words to describe your pain.

How bad is the pain? You can also use a number scale and rate your pain from 0 to 10: 0 means no pain and 10 means the worst pain. You may want to use the pain intensity scale on page 19 to put a number to your pain. You can also describe your pain with words like none, mild, moderate, severe, or worst possible pain.

What makes the pain better or worse?

You may have already found ways to make your pain feel better. For example, using heat or cold, or taking certain medicines. You may have also found that sitting or lying in certain positions or doing some activities affects the pain.

If you are being treated for pain now, how well is the treatment working? You may want to describe how well the treatment is working by saying how much of the pain is relieved—all, almost all, none, etc.

Has the pain changed? You may notice that your pain changes over time. It may get better or worse or it can feel different. For example, the pain may have been a dull ache at first and has changed to a tingle. It is important to report changes in your pain. Changes in pain do not always mean that the cancer has come back or grown. Describe how the pain was before and how it is now.

After talking with you about your pain, your doctor or nurse may want to examine you or order x-rays or other tests.

These tests will help the doctor or nurse find the cause of your pain.

Having a Plan

You can work with your doctor or nurse to write a pain control plan to meet your needs. In a pain control plan, you and your doctor or nurse plan your pain control activities. This will include when to take your medicine, how and when to take extra medicine, and other things you can do to ease and prevent your pain. Your doctor or nurse may also list the medicines and other treatments you can use to help you with any side effects or other aches and pains, such as headaches. A sample pain control plan that you can use is on pages 20-21.

Making the Plan Work

Some people find that the first pain control plan does not work for them. You and your doctor or nurse can change your pain control plan at any time. Here are some questions to ask yourself about the pain plan:

Is the pain plan hard to follow?

Is there any part of the plan that is hard to understand?

Are you pleased with the pain control?



Are you having trouble getting the medicine?

Are you having trouble taking the medicine?

Are you having side effects from the medicine?

Is the medicine or the treatment causing a problem for you or your family?

Are the nondrug treatments working for you?

Write any other questions you have for your doctor or nurse below.

Benefits and Risks of Treatment

This booklet talks about many different treatments for cancer pain. It also talks about side effects of medicines.

Information about benefits and risks (side effects) of medicines may also be important to you. The list below describes the benefits and risks of the different types of medicines described on pages 4-5.

Nonopioids:

Benefits: Control mild to moderate pain. Some can be bought without a prescription.

Risks: Some of these medicines can cause stomach upset. They can also cause bleeding in the stomach, slow blood clotting, and cause kidney problems. Acetaminophen does not cause these side effects, but high doses of it can hurt the liver.

Opioids:

Benefits: These medicines control moderate to severe pain and do not cause bleeding.

Risks: May cause constipation, sleepiness, nausea and vomiting. Opioids sometimes cause problems with urination or itching. They may also slow breathing, especially when they are first given, but this is unusual in people who take opioids on a regular basis for pain.

Antidepressants:

Benefits: Antidepressants help to control tingling or burning pain from damaged nerves. They also improve sleep.

Risks: These medicines may cause dry mouth, sleepiness, and constipation. Some cause dizziness and lightheadedness when standing up suddenly.

Anticonvulsants:

Benefits: Help to control tingling or burning from nerve injury.

Risks: May hurt the liver and lower the number of red and white cells in the blood. It is important to have regular blood tests to check for these effects.

Steroids:

Benefits: Help relieve bone pain, pain caused by spinal cord and brain tumors, and pain caused by inflammation. Steroids also increase appetite.

Risks: May cause fluid to build up in the body. May also cause bleeding and irritation to the stomach. Confusion is a problem for some patients when taking steroids.

Counseling and Peer Support

Pain can make you feel many emotions. You may feel sad, helpless, vulnerable, angry, depressed, lonely, isolated, or other emotions. Lots of people feel these things when they are in pain. Often, when the pain is successfully treated, these feelings lift. Many people who have had cancer feel that counseling, religious, and other support groups have helped them to get back a sense of control and well being.

To find out more about support groups and to receive books and pamphlets about cancer pain, call or write to:

- National Cancer Institute
Cancer Information Service
800-4-CANCER

Ask for the booklet *Questions and Answers About Pain Control*.

- American Cancer Society
800-ACS-2345

The booklet *Questions and Answers About Pain Control* is also available from this group.

- Wisconsin Cancer Pain Initiative
Medical Science Center, Room 3675
University of Wisconsin
Medical School
1300 University Avenue
Madison, WI 53706
608-262-0978

For adults, ask for *Cancer Pain Can Be Relieved*.

For children with cancer pain, ask for *Children's Cancer Pain Can Be Relieved*. For adolescents with cancer pain, ask for *Jeff Asks About Cancer Pain*.

Slow Rhythmic Breathing For Relaxation

Deep breathing exercises can help relax you. These exercises may work along with your medicine to lessen or relieve your pain.

1. Breathe in slowly and deeply.
2. As you breathe out slowly, feel yourself beginning to relax; feel the tension leaving your body.
3. Now breathe in and out slowly and regularly, at whatever rate is comfortable for you.
4. To help you focus on your breathing and breathe slowly and rhythmically:
(a) breathe in as you say silently to yourself, “in, two, three”; (b) breathe out as you say silently to yourself, “out, two, three.” or

Each time you breathe out, say silently to yourself a word such as “peace” or “relax.”

5. Do steps 1 through 4 only once or repeat steps 3 and 4 for up to 20 minutes.
6. End with a slow deep breath. As you breathe out say to yourself “I feel alert and relaxed.”

Source: McCaffery and Beebe, *Pain: Clinical manual for nursing practice*, 1989. Adapted and reprinted with permission.

Pain Control Plan

Pain control plan for _____

At home, I will take the following medicines for pain control:

Medicine	How to take	How many	How often	Comments
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____
_____	_____	_____	_____	_____

Medicines that you may take to help treat side effects:

Side Effect	Medicine	How to take	How many	How often	Comments
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____
_____	_____	_____	_____	_____	_____

Constipation is a very common problem when taking opioid medications. When this happens, do the following:

- Increase fluid intake (8 to 10 glasses of fluid per day).
- Exercise regularly.
- Increase fiber in the diet (bran, fresh fruits, vegetables).
- Use a mild laxative, such as milk of magnesia, if no bowel movement in 3 days.
- Take _____ every day at _____ (time) with a full glass of water.
- Use a glycerin suppository every morning (this may help make a bowel movement less painful).

Nondrug pain control methods:

Additional instructions:

Important phone numbers:

Your doctor _____

Your nurse _____

Your pharmacy _____

Emergencies _____

Call your doctor or nurse immediately if your pain increases or if you have new pain. Also call your doctor early for a refill of pain medicines. Do not let your medicines get below 3 or 4 days' supply.

For Further Information

The information in this booklet was taken from the *Clinical Practice Guideline on Management of Cancer Pain*. The guideline was written by a panel of private-sector experts sponsored by the Agency for Health Care Policy and Research. Other guidelines on common health problems are being developed.

To order a single copy of this booklet call the National Cancer Institute, Cancer Information Service at:

800-4-CANCER

or write to:

Cancer Pain Guideline
AHCPR Publications Clearinghouse
P.O. Box 8547
Silver Spring, MD 20907



U.S. Department of Health and Human Services
Public Health Service
Agency for Health Care Policy and Research
Executive Office Center, Suite 501
2101 East Jefferson Street
Rockville, MD 20852

AHCPR Publication No. 94-0595
March 1994