

CHOICES

Living with cancer
Dying with dignity

SECOND EDITION

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— Molly Sower Sugarman



**SUPPORT THE BLUE RIBBON CAMPAIGN TO
FIND A CURE FOR PROSTATE CANCER**

WHAT CANCER CANNOT DO

CANCER is so **LIMITED**

It **CANNOT** cripple love

It **CANNOT** shatter hope

It **CANNOT** corrode faith

It **CANNOT** destroy peace

It **CANNOT** kill friendship

It **CANNOT** suppress memories

It **CANNOT** silence courage

It **CANNOT** invade the soul

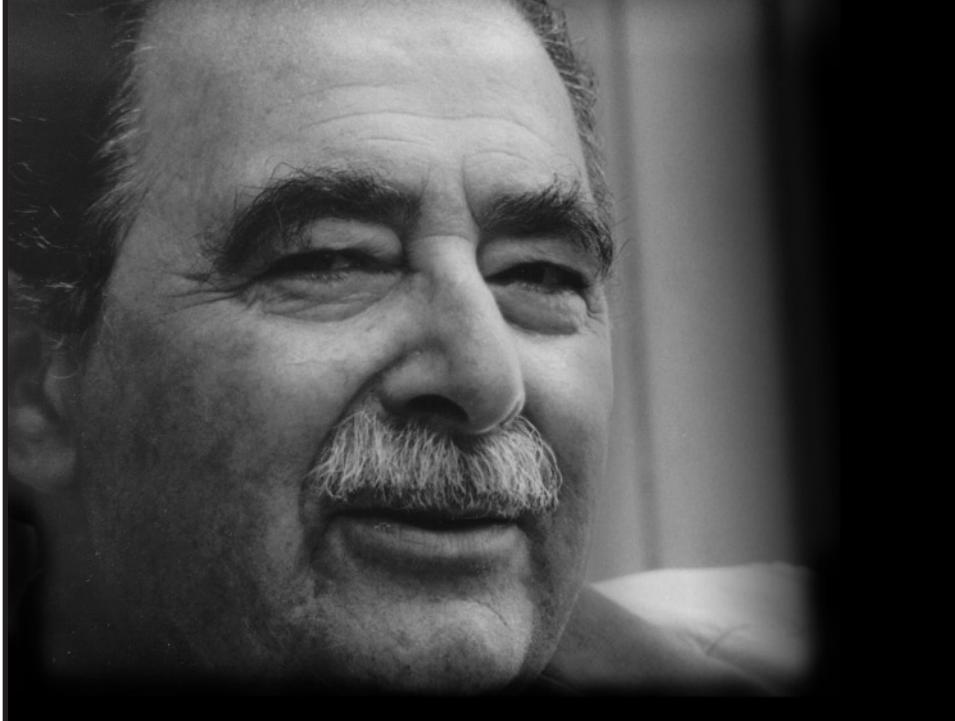
It **CANNOT** steal eternal life

It **CANNOT** conquer the spirit

— anonymous

CONTENTS

3	INTRODUCTION
5	MAKING REALISTIC DECISIONS
	Facts to consider
	Palliative care
	Asking questions
11	PAIN MANAGEMENT
14	EASILY BROKEN BONES
17	LOW BLOOD COUNTS
19	FATIGUE
	Public image
23	LOSS OF MUSCLE TONE
24	EDEMA
26	SHORTNESS OF BREATH, COUGHING AND LUNG DISCOMFORT
28	WEIGHT LOSS, NAUSEA AND LOSS OF APPETITE
30	HOSPICE
32	RESOURCES



Seasons

*what a wonder you are
 chiding me
 loving me
 believing in me
 I tremble at the steps I must take
 unknown territory
 unsettled weather
 no map
 no path
 knowing I must go on
 alone
 but knowing I'm loved
 a fire in my heart
 to warm me in this cold season
 new buds will form
 telling of spring*

—Matthew Sugarman

MATT

From 1994 to 1999, Matthew Sugarman was a cancer survivor. His PSA had been checked regularly but never registered high. It was still normal on the day he was diagnosed with metastasized prostate cancer.

In April 1998, increasing tiredness and a broken rib prompted sharp questioning of his doctor, who reluctantly admitted that healing was not an option. There were no tools or knowledge left with which to save Matt's life; we would have to figure out how to die. Matt's days were numbered in months — three to six — time that could almost be counted on one hand.

Matt outlived all predictions. He simply did not want to leave. During this time, we learned many things about cancer and many things about choices. Most of this knowledge was acquired through questioning and our own experience, as we couldn't find

any literature that discussed this twilight zone between ending treatment and entering the final stages of death. For thirteen months, we filled Matt's dying with more life than anyone imagined possible. Then one afternoon in May, everything stopped. The destruction of his body ceased, and with it, his life.

The knowledge we acquired is not new. Dying, after all, is as old as the earth. Perhaps this compilation of what we found will make the process a little less confusing and frustrating to others. We want to leave something behind: a note or a map, to give some relief to others on this journey.

In 1996, Matt wrote *Seasons*, a poem about love, but now it seems equally about death. A man, a wife, a patient, a caregiver. And an irrevocable change in circumstance.

a true story

fiercely independent,
strong, proud, he vowed
to shoot himself when he
became disabled

two years later

mush, mush! laughter shouts of joy he
is in a wheelchair careening down a
path yelling mush to the husky and the
daughter who are pulling the chair

all of them loving life

REALISTIC DECISIONS

Most men do not die of prostate cancer; some do. This booklet is designed to help those whose cancer has advanced and who will likely, at some unknown time, die of prostate cancer. The purpose is to give them and their caregivers a sense of the journey on which they are about to embark.

Once prostate cancer has metastasized, it cannot be cured. Hormone ablation therapy, such as Zolodex, and chemotherapy are aimed at slowing the spread of the cancer. Local radiation to eliminate a specific lesion may be used to reduce pain. Radiation also kills the cancer cells in a specific location but it does not kill all the cancer cells on the loose in your body and probably will not cure you.

Many clinical trials and experimental programs fall into these same categories – that is, slowing the spread of the cancer or reducing pain. A few will try to eradicate the cancer cells throughout your body and effect a cure.

Metastasis indicates that cancer cells have escaped into the body, where they may be producing tumors not yet visible on bone scans or other tests.

Prostate cancer can spread to organs as well as bones; it can overwhelm the liver or the kidneys. Severe changes in mental ability, such as hallucinations and confusion, may indicate metastasis to the brain. It is important to remember, however, that fatigue can reduce mental ability temporarily, and rest may be enough to solve the problem.

Any change in your body, whether discomfort or changes in how it works – such as frequency of urination, color of urine, etc. – should be reported to your doctor. Sometimes the cause will be easily corrected and your mind and body can be put at ease. Other symptoms may be indications that the cancer is progressing and, therefore, indications that you and your family have decisions to make regarding the quality of life and the treatments you want.

Each treatment has side effects and each has its own likelihood of being effective. It is up to you and your family, with the help of your doctor, to evaluate the treatment, its chance of success and its side effects, before deciding if you want the treatment. Your choice will depend on your expectations. Some people don't want to stop trying until the doctor runs out of things to try. Other patients say, "I don't want to go through all that for so little gain; it's a bad bargain. I'd rather spend less time with the doctor and more time fishing."

The choice is yours.

Even at this stage, when life is measured in months rather than years, there are battles left to fight, and many to win. It is not a time for hopelessness. It is time for tough choices about how you will cope with the effects of the disease and how, and at what level, you will maintain the quality of your life. It is not time to surrender. It is time to realize that, in the end, your war against cancer will probably be lost.

To make the most of this part of your life, you must ask questions and evaluate what is important to you.

Facts to consider

A few facts may help you organize your thoughts.

- Once cancer has been detected outside the prostate, it may be present

throughout the body in amounts that are not yet detectable by medical technology.

- If your bone scan shows one lesion, it is safe to say that other bones may also be weakened by cancer, although the damage is not yet severe enough to be detected on a bone scan.
- Cancer in the bone marrow does not appear on bone scans, although it may show up on other tests. If a lesion has shown up on a bone scan, the disease probably will affect your body's ability to produce red and white blood cells and platelets.
- In a process not yet fully understood by medical science, cancer cells "poison" the body and hijack healthy cells. The cancer cells release proteins and material that cause inflammation. As time goes on, this toxicity will become more apparent in a feeling of general ill health, as if you have the flu. You may be tired, lethargic, achy, and have fevers and chills.
- The effort to clean your body of this unwanted material eventually strains your liver and kidneys. When these organs become overloaded, they may fail. You may have to consider treatment that will help your kidneys and liver process the toxins produced by the cancer cells.

Make the most of this part of your life. The choice is yours.

Ask questions and decide what is truly important to you.

- When a treatment is offered with a "40 percent chance of lowering your PSA," it also has a 60 percent chance of *not* lowering your PSA. The side effects of the treatment may be significant. Take into consideration the chance of failure as well as the chance of success when deciding whether to undergo the treatment. The side effects will probably be the same whether the treatment succeeds or fails.
- This question of quality of life is important. Some people feel that three months of debilitating side effects are too much when they have a year to live; they'd rather live a shorter, more comfortable life. For others, it is more important to take advantage of any opportunity to prolong life.
- The cancer is "hormone-independent" when your PSA rises even though you are taking hormone-suppressing drugs. When this happens it is harder to slow the spread of the cancer because some cancer cells can now grow without testosterone. You will probably continue hormone treatment, however, because not all cancer cells become hormone-independent. The growth of some cells is still stopped by the hormone-ablation treatment. In

other words, the spread of the cancer can still be slowed somewhat. Stopping all hormone treatment may cause increased bone pain and more rapid spread of the disease.

- Get a second opinion. Try to get a consultation with a doctor outside your normal health plan or medical group, to be sure that medical care, not HMO rules, are dictating responses. A consulting doctor will have different experiences and possibly new information. Even if the second doctor confirms your physician's recommendation, you will have more confidence in the information upon which you base critical decisions.
- Get a third or fourth opinion if the first doctors don't answer your questions or honor your right to take charge of your care.
- Any doctor's estimate of your life expectancy is an educated guess, not a certainty. You may live longer or die sooner than the doctor's estimate, depending on the choices you make, your body's response to treatment, and the aggressiveness of the cancer. If there is something that you really want to do, do it now. Don't sit back and wait to die. Keep living and planning.

Men do survive prostate cancer and die of something else. Men also die of prostate cancer. Of the 180,400 new cases of prostate cancer expected in America in 2000, 89 percent will survive at least five years and 63 percent will survive 10 years, according to the American Cancer Society. But the ACS estimates that in 2000 31,900 men in the United States will die of prostate cancer, accounting for about 13 percent of male cancer-related deaths.

If the tide of your fight against cancer turns, treatments are less likely to slow the spread of the disease. The effect of the cancer on your bones, blood and other organs will become more obvious and your quality of life will be affected. You may still be working and participating in community activities, sports and household chores. With adjustments, you may continue to do so for some time.

Your body will tell you when the shift of power has taken place; symptoms will occur that should alert you that you might not survive the disease.

These symptoms do not occur in any specific order or on any particular time-line. Some patients may experience only one or two of the symptoms; others may experience many or none. The appearance of these symptoms does not mean you have three months or six months or any other specific amount of time remaining. It does mean that the balance of power

between your body's strength — even augmented by medical treatment — and the cancer's strength has changed. Cancer is getting the upper hand.

Palliative care

The symptoms outlined in this booklet should be discussed with your doctor. Ask blunt questions about your prognosis and about “palliative” treatments. Palliative treatment is treatment designed to maintain quality of life, minimize pain and keep you active as long as possible. Its primary focus is not curing the disease but maintaining good quality of life.

Asking questions

Talk frankly and openly to your doctor. It is the most important thing you can do. Be in touch with your body and check out anything new or different. Make a list of questions you want to ask as you think of them and take the list, no matter how long, to your doctor.

Try to have someone come with you when you talk to your doctor to help you ask questions and interpret answers. Take notes or tape-record the answers so you can review the information with family members or refresh your own memory.

Do not accept evasive answers. Do not accept answers that are too complex for you to understand. Repeat your questions until you understand the answer.

Ask if a symptom is a sign the disease is progressing, or if it is the side effect of treatment, and if there is anything that can be done to give you more comfort. The answer may be that the symptom you are concerned about has nothing to do with the cancer. That, too, can be useful knowledge. It gives you one less thing to worry and wonder about.

Some patients decide to make no changes in the way they are living. Others decide to take a long-desired trip or spend more time with family or friends. For some, these symptoms prompt the writing of a will and preparation of instructions regarding end-of-life medical care. For others, it is an opportunity for self-evaluation and reconciliation.

Don't sit back and wait to die. Keep living and planning.

It is not a time for hopelessness.

Always ask how any change affects your prognosis, that is, the likelihood you will survive the disease or how long you will survive. Many doctors will not discuss your future unless you indicate that you want to know. They are waiting for you to ask questions. Remember that their answer is a guideline, not a schedule.

If your doctor is reluctant to discuss your prognosis or does not seem to be giving direct answers to your questions, keep asking or, if possible, change doctors. One good question to ask, and demand an answer to, is “What would you do in my situation?”

You also need to look at what effect, if any, the symptom or the change in your body will have on your life-style.

The symptoms themselves may force changes in lifestyle and in relationships. For example, increased fatigue cannot be eliminated or ignored. Making time in your daily schedule for rest is a change you may be forced to make.

As you read this booklet, you may say “I never want to be that sick! I'll kill myself first.” Don't be too sure. An evolution will occur, not a revolution. You won't wake up tomorrow bedridden. Your body will change over time. As it does, so will your mind. Your perspective, values and fears are not the same as they were five years ago. They wouldn't be the same five years from now, even if you didn't have cancer. Don't make decisions before you have to, before you have all the information.

PAIN MANAGEMENT

Pain is the most common problem faced by men with metastasized prostate cancer. It is a problem with various causes and many effective solutions.

Cancer pain can be caused by damage to organs, bones, muscles or joints. It can be caused by a tumor that has grown so large that it prevents proper functioning of other parts of the body, such as the digestive system or colon. Cancer also causes pain when a tumor presses against nerves or the spinal cord itself.

If you try to fight pain and tough it out, you will enjoy life less, and will be tired and depressed.

Palliative measures

Most cancer pain can be controlled or even eliminated. In its publication, *Home Care Guide for Advanced Cancer*, the American College of Physicians states that pain can be controlled for 90 to 99 percent of cancer patients.

Control of pain may be as simple as taking aspirin on a regular basis. When pain persists, narcotics, such as codeine, morphine or synthetic versions of them may be prescribed. Most of these drugs take a few days to

become effective. If pain continues, ask your doctor about increasing the dose or changing medicines.

Pain medication falls into two categories: baseline, which provides constant pain relief, and “breakthrough” medication for pain spikes that break through the baseline occasionally. Keep track of how often you take breakthrough medication and why. Mark it in your calendar or keep a pain log.

If breakthrough medication is needed frequently, ask your doctor about increasing the baseline medication or switching to another medicine. If a particular part of your body is hurting frequently, such as your hip, it may be possible to eliminate the pain by other means, such as localized radiation.

Addiction is not an issue when you have advanced cancer. “Saving” pain medication for a really bad bout is unnecessary. “Bad bouts” can be treated with stronger medicines or by other techniques.

Chemical pain medication comes in pills, time-released capsules, and skin patches that last as long as 72 hours.

IN THE DEPTH OF WINTER,
I FINALLY LEARNED THAT
WITHIN ME THERE LAY
AN INVINCIBLE SUMMER.

— ALBERT CAMUS

Radiation of particular tumors or lesions on the bones also relieves pain. Strontium-89 is an injected radiation treatment that irradiates lesions in bones throughout the body. It usually provides significant pain relief for three to six months.

Strontium-89 treatment affects healthy bone marrow as well. This may result in a drop in the red blood cells used to carry oxygen throughout the body and in platelets needed for blood to clot. This side effect may require treatment itself. (See *Low Blood Counts*). Because of this side-effect, Strontium-89 can be used only a few times.

Addiction is not an issue in treating advanced cancer pain.

Monthly infusions of pamidronate, which is used to strengthen bones, may also reduce pain.

Eliminating pain can eliminate fatigue, lethargy, stress and lack of interest in normal activities. Working through pain uses a lot of energy and may become a barrier to normal activity.

Alternative methods are often used along with medical methods to relieve pain. Acupuncture has been proven

to relieve some pain. Meditation and visualization are useful. Massage can also help, whether a full-body professional massage or a foot massage by a friend.

The most important thing to remember about pain is you don't need to have it. If a medication doesn't work within a few days, ask your doctor for something else.

Lifestyle considerations

You must become a clock-watcher when on pain medication. To work effectively, pain medication must be given *before* pain starts and on a regular basis to maintain a steady level of medi-

cation. Sleeping through a scheduled dose allows pain to reappear. It is much harder to eliminate pain than to prevent it.

Set an alarm clock to remind you when the dosage is due. When you take your medicine, reset the alarm for the next dose. For longer acting drugs, mark your calendar.

If your medication lasts four to six hours, you must get up in the middle of the night to keep on schedule.

The most important thing to remember about pain is that you do not have to have it.

Some pain medication can be provided in 12-hour capsules, which makes adhering to your schedule easier.

Pill boxes with timers are available to make sure you don't miss a dose whether at work or at home. With or without a timer, always carry a pill box in case you get home late or experience breakthrough pain. Both your baseline and breakthrough medications should be within reach at all times.

Patches, such as fentanyl, that deliver pain medication at a steady rate for 72 hours are a relief from clock-watching. As the need for pain relief increases, more patches can be added.

Although patches allow freedom from daily clockwatching and reduce the likelihood of forgetting your pain medication, they have other problems. Patches can be difficult to apply. The steady delivery of the medication may be affected if the edges come loose.

Johnson & Johnson makes a patch to go over the fentanyl patch. It prevents the medication patch from lifting up. Or, tape the edges of the fentanyl patch down with medical tape.

The adhesive on the fentanyl patches may cause an allergic reaction. As a result, the skin may become red and sore where the adhesive touches the skin.

To eliminate the allergic reaction, hydrocortisone cream can be spread on the area before the patches are applied. After allowing time for the cream to be absorbed, thoroughly wipe the area to remove all greasiness and apply the patch.

Removing the patches can be painful. It is easier if the patches are pulled off after a hot shower.

Strong pain medications almost always cause constipation, which can be severe and painful. A good rule of thumb is to take a stool softener every time you take pain medication. Ask your doctor about the kind and amount you should take. Adjust the dosage of stool softener as the dosage of your pain medicine is increased.

All these methods of pain relief require discipline. But all are portable, easy to use and will not interfere with activities, such as work and travel.

EASILY BROKEN BONES

Prostate cancer most commonly spreads to the bones. When normal activities, such as pruning a tree or lifting a box, cause a broken bone, it is a sign that cancer has weakened the structure of the bones. Like a person with osteoporosis, the bones are brittle and cannot withstand pressure.

While a break or multiple breaks may take place where lesions have already been noticed on bone scans, it is important to remember that cancer, in undetectable amounts, may be present and affecting other bones. You cannot assume that future breaks will occur only where there are visible lesions.

Palliative measures

Medicine has been developed that enhances the body's ability to rebuild bone. Studies also indicate that given as often as once a month, this medicine — pamidronate — may reduce bone pain and therefore the amount of pain medication needed.

Local radiation also destroys the targeted lesion and makes the bone less likely to break. Radiation is limited, however, and cannot be used repeatedly on the same site.

Report any pain to your doctor and talk about treatment options.

Lifestyle considerations

Some breaks, such as an arm or rib, may be painful and inconvenient. Others, such as a broken hip or spine, could cause drastic and premature loss of mobility.

You may need to become more cautious in the activities you undertake in order to lessen the likelihood of breaking any bones, but most particularly the bones of the spine and hips. White-water rafting, for example, may be ruled out but fishing or sailing might be all right. Heavy work, such as chopping wood or pruning trees, may have to be delegated to someone else, whether a family member or hired help.

The need for caution will affect both you and your family. For example, your caregiver may become overly cautious and worry about any activity you undertake. Or, you may become so careful that you limit your activities more than necessary.

You may need to become more cautious in your activities to avoid breaking any bones.

Some men find it hard to accept a new, limited way of life. They may choose to continue now risky activities. That, too, is a decision that will affect the caregiver as well as the person with cancer.

You or your caregiver may become resentful of the shift in responsibilities. Talk about the changes and mutually decide how they can be handled to avoid resentment, overburdening your caregiver, excessive caution, or risk-taking that creates worry and stress. Talking about the problems may help you think of creative solutions.

New approaches to old tasks may help. Breaking jobs down into smaller parts may reduce physical strain. Instead of lugging one heavy can of garbage to the curb, maybe the trash should be split between two containers so the strain is less.

Instead of fishing where access to the river is steep with bad footing, find a new place with easier access, and take a walking stick to steady yourself.

You, your family, and your doctor should discuss reasonable limitations and new approaches to tasks so you can have an active and enjoyable life as long as possible.

It is very important that you maintain as much mobility as possible. Don't allow someone else to do tasks you can safely and painlessly do yourself. You may not be able to lift the garbage cans, but you can get up to let the cat out.



LOW BLOOD COUNTS

If cancer affects your bone marrow, the marrow will produce fewer and fewer of the blood cells essential to your well being.

Bone marrow produces red blood cells, which carry oxygen. With too few red blood cells, your body does not have enough oxygen and you become tired and breathless. Giving you oxygen may not be a solution. It is not lack of oxygen intake that is causing the problem; it is lack of cells to carry the oxygen.

Low white-cell counts increase your risk of infection. Too few platelets reduces the ability of blood to clot.

Low blood counts may be caused by treatment, such as radiation. In that case, the effects on your bone marrow may wear off over time and the cell counts may go up again. Low blood counts may also result when cancer destroys the cell-making capacity of the bone marrow or when the cancer kills blood cells faster than the marrow can make new ones.

If the cancer has destroyed the bone marrow's ability to produce blood cells, palliative measures are available to help maintain your quality of life but these measures will not cure the problem.

Palliative measures

If blood counts are low due to treatments, such as radiation, medication may “jump start” the bone marrow. Usually the medicine is given in a series of injections. You may be able to give the injections yourself. If this is successful, the blood counts will rise and the symptoms – breathlessness and fatigue – may lessen.

Eventually, the toxic effect of the cancer on all body systems will probably increase, making fatigue and breathlessness unavoidable. You may be less able to perform daily tasks simply because you don't have the energy.

Blood transfusions can increase the number of red blood cells available



Dealing with it is the operative word.

I found myself at seven years not battling it.

Not breaking under the burden of it.

Not struggling with it.

But dealing with it.

— Michael J. Fox



to carry oxygen. Your doctor can test your blood on a regular basis and, if the cell counts are low, order the transfusion of whatever amount of blood he or she feels will reduce your fatigue. One standard is to order blood transfusions when your hematocrit falls below 30.

Because the bone marrow is not replenishing the red cells naturally, this outside replenishment may be ordered repeatedly, on a monthly or more frequent basis, as needed. When

blood counts are discussed in the next sections, *Fatigue and Shortness of Breath*.

White blood cells cannot be transfused. Because of the increased risk of infection when white counts are low, your doctor may suggest immunizations for flu and pneumonia, or avoiding people who have contagious diseases. You will want to pay attention to health alerts aimed at people with reduced immune systems. Report any fever to your doctor for early antibiotic therapy, if needed.

Because white blood cells cannot be transfused, you should pay attention to health warnings for people with impaired immune systems

blood transfusions are required frequently, you may want to consider whether the time spent traveling to the medical center and getting the treatment is worth the benefit received. This is one of the many choices you have to make between treatment and quality of life.

Lifestyle considerations

Techniques for dealing with the fatigue and the breathlessness of low red

Low platelet counts may cause problems with clotting and reduce the body's ability to stop bleeding, even from minor cuts and scrapes, such as those that occur while shaving. Tell your doctor about any sign of bleeding, such as a nosebleed or blood in your urine or stool.

You may bruise more easily. If this happens, talk to your doctor about medicines, food or herbs that increase the clotting ability of blood.

FATIGUE

You may notice that even on a relaxing day, you become very tired in the afternoon. Or you may find that you cannot finish projects because you are suddenly overwhelmed by fatigue. You may be unable to keep your eyes open or feel as if you cannot move out of your chair. Tasks that were once simple may seem too complicated to understand. All of these symptoms can be attributed to fatigue.

While sleepiness may be caused by pain medication – especially when taking a new prescription or dosage – fatigue is usually not caused by medication. If pain medicine is used correctly, you will probably feel more energized, not less, because you are sleeping better and not worn out by the pain itself.

Fatigue is caused by the cancer. In a process not fully understood by medical science, the cancer cells release toxins. Like any toxic substance, these cytotoxins weaken your system. As your body attempts to fight the foreign materials released by the cancer cells,

you become tired and feverish, just as you do when fighting any illness. The liver and the kidneys may be strained, and begin to fail.

As mentioned in the section, *Low Blood Counts*, the number one cause of fatigue is impairment of the bone marrow and its inability to produce enough red blood cells to provide your body with the oxygen it needs.

Palliative measures

Depending on the cause of the fatigue, blood transfusions or changes in medication or the use of oxygen may help. So, too, may changes in lifestyle.

Lifestyle considerations

Fatigue is one of the most insidious and most irritating symptoms of cancer's progress. It can come upon you suddenly, giving you the feeling that all the energy has drained out of your body and you cannot move another step. You may find yourself panting after one flight of stairs. Or you may simply take less pleasure in events and people because you are tired.

Schedule activities so you don't plan too much on one day

You may need to set aside time each day for rest

Mental fatigue is most devastating to self-esteem and relationships. When the body's resources are strained, the body focuses its energy on essential physical systems. Mental processes shut down. Balancing the checkbook as you usually do suddenly may seem confusing. Planning your daily schedule may be overwhelming. Easy questions may evoke a sharp response because you don't understand what is being asked. You simply can't process information as well as you usually do, no matter how hard you try.

Mental fatigue is disruptive because, at first, neither you nor your family may realize what is happening. You may seem cranky or uncooperative rather than tired. Be aware that you may be experiencing severe fatigue. The awareness can help both you and your family avoid stress.

For example, if you are having trouble with the checkbook or a legal document or following a story, take time out. Rest or sleep, then try again. Do important work when you are at your best. For some, that is in the morning; for others, it may be later in the day or after a nap.

You and your family need to look out for signs that you need rest, such as body language or lessened ability to participate in conversations. Learning to recognize the signs will help you stop before you become overtired, and before you and your family make decisions based on frustration rather than careful consideration of the facts and options.

To accommodate fatigue, you may need to work fewer hours each day; you will certainly have to pace your activities. Busy days, whether family gatherings or trips to the medical center, may need to be followed by days of rest.

You may need to set aside time each day for rest.

Scheduling of activities will become important in order to avoid planning too many things on one day. If you plan to go to work in the afternoon, you probably should not do household chores in the morning.

One way to save energy is to ask friends to come over instead of visiting them. Instead of cooking dinner, meet at a restaurant, order a pizza or ask your visitors to bring food.

If confusion and changes in ability to think are not reduced by rest, something else may be wrong. One possibility is hypercalcaemia, which is caused by too much calcium in the blood. Your doctor can check your blood calcium levels with a blood test. If you're constantly confused and thirsty, and urinate frequently, ask your doctor to check for hypercalcaemia.

Remember that as you do less, your caregiver must do more. His or her fatigue must also be considered in your schedule. Set aside time for your caregiver to relax. Find ways to lessen the energy required for everyone's chores. This may mean asking someone to help with cleaning or yard work, or it may simply mean that you approach tasks creatively.

Learning to recognize the signs of fatigue enables you to rest before you get too tired

Friends and relatives may be eager to help but at a loss about what they can do. Let them mow the lawn, pull weeds, clean the house and go to the grocery store. You and your caregiver will have more time to relax together, and your friends and family will have the satisfaction of "doing something."

Find ways to conserve energy. Instead of carrying your baggage onto the plane, check it at the curb. Get a handicapped parking tag so you can shorten the walk to the theater,

the mall or business appointments. Use a wheelchair to tour the museum instead of walking.

Each of these changes in the way you do things represents a choice. You may choose to tour part of an exhibit on your feet rather than see everything from a wheelchair. It is important, however, for you to realize that you have choices. "Reduced energy" is not the same as "no energy;" changing how you do things is not the same as giving up the activities that give you pleasure.

Most cancer centers have pamphlets about fatigue because this is a side effect of many treatments as well as a symptom that the cancer is spreading.

Public Image

Many of the suggestions for dealing with fatigue represent a public, although unspoken, statement that you are "less able" than you were. It is hard psychologically to sit in a wheelchair when you have been active. Letting someone do your chores or having your co-workers take over your work is hard to accept. Talk to your doctor, your family, the cancer center social workers and other patients about these losses and your options.



*Oh my friend,
It's not what they take away from you that counts —
it's what you do with what you have left.*

— Hubert Humphrey

LOSS OF MUSCLE TONE

Fatigue and reduced activity may lessen muscle tone. Less strength and stamina are expected, but it is important to do as much as possible to work your muscles. Without some muscle-toning exercise, you may become dependent on others to help you turn in bed or get up out of a chair. Contractions of the leg muscles pump blood back to the heart, so you may get dizzy when you stand up if your leg muscles are weak.

As cancer progresses, the body begins to use protein instead of fat for energy, causing muscle wasting and undermining organ functioning.

Palliative measures

While strenuous, body-building efforts should be avoided, simple exercises may allow a more satisfactory quality of life. Lifting light weights, such as 3-lb. dumbbells or using light-resistance rubber exercise bands may maintain enough muscle strength to keep you independent longer. Gentle range-of-motion exercises for your joints may help you retain mobility.

Walking is good exercise. If fatigue prevents long walks, walk around the

yard. You can go to a park, walk as long as is comfortable, then continue in a wheelchair. (Hospice or your medical insurance may provide a wheelchair that can be transported in the trunks of most cars.) Walks also give you and your caregiver fresh air and a change of scene.

Consult your doctor or physical therapist about any exercise you do.

Life-style considerations

Tiredness and prohibitions against strenuous tasks may lead you to accept being waited on. But you and your caregiver should realize that getting up to get your own coffee is good for you, as long as it does not cause pain and as long as you are not severely fatigued.

While it may be easier and quicker for your caregiver to do such tasks, you will benefit more from doing them when possible. The goal is not to overtax yourself, only to prevent premature loss of the ability to perform simple tasks. You may not be able to vacuum the entire house, but you may be able to vacuum one room or part of one room.

EDEMA

You may notice that your doctor checks your calves and feet when examining you. S/he is looking for fluid retention. If pressing the skin moderately leaves a mark that fades slowly, you may be retaining fluid nor-

scrotum may cause discomfort. The lower abdomen may swell and appear bloated.

Lymph nodes in the neck or other parts of the body may also become swollen and painful.

If pressing your skin moderately leaves a mark that fades slowly, you may be retaining fluid normally processed by the lymph nodes.

mally processed by the lymph nodes. Cancer cells may collect in the pelvic lymph nodes, causing temporary or longer-term blockage of the flow of lymphatic fluid. The blockage may eventually cause swelling, pain and difficulty walking.

If the scrotum swells, the testicles may be forced up into the body where they are not easily felt. The enlarged

Swelling may also be caused by urinary retention, which can result from bladder or kidney damage. The onset of urinary retention can look like edema. If swelling continues despite treatment for edema, ask for a creatinine test. High creatinine levels are indicative of urinary retention. Treatment may include a catheter to release backed up urine.

Ask your doctor what you should do.

Discuss changes with your family

to minimize the impact on your quality of life.

Palliative measures

Elevating your feet may relieve swelling caused by edema in pelvic lymph nodes. Diet may be a factor. Salt encourages fluid retention. A high-salt diet, added to the extra burden of filtering cancer cells, may block the lymph nodes. Reducing salt intake or taking a diuretic may help. Sometimes wearing briefs instead of boxer shorts will be recommended to minimize edema. Wearing an athletic supporter may be suggested.

In serious cases, physical therapy may be used to induce drainage of the lymph fluid trapped in the legs. The legs, and possibly the scrotum, may be wrapped to discourage fluid retention.

Swollen lymph nodes, such as those in the neck, may be treated with radiation if the cancer is the cause of the swelling.

Lifestyle changes

Like all treatments, scrotal or leg wraps may require visits to the doctor or from hospice staff. Family members may be required to learn new skills. Diet or clothing changes may be called for or you may need to set aside time each day to sit with your feet elevated.

Ask your doctor what you should do. Discuss changes with your family to minimize the impact on your quality of life.

SHORTNESS OF BREATH, COUGHING AND OTHER LUNG DISCOMFORT

Low blood counts are not the only cause of shortness of breath. Prostate cancer may metastasize to the lungs and other organs or soft tissue. Shortness of breath may be a symptom of the spread of cancer to the lungs. If so, ask your doctor about treatments and your prognosis.

Shortness of breath, accompanied by pain, may indicate that bone lesions on the underside of the ribs are irritating the lungs or that a rib has broken.

Palliative measures

Anti-inflammatory drugs, such as ibuprofen, may reduce pain caused by a rib lesion or a broken rib. Check with your doctor before using any drugs.

Home oxygen can be used to decrease the feeling of breathlessness. If the shortness of breath is severe and limits your ability to go out, portable oxygen tanks are available.

Breathlessness should trigger questions to your doctor about prognosis, treatments, and measures to improve your comfort.

Lifestyle considerations

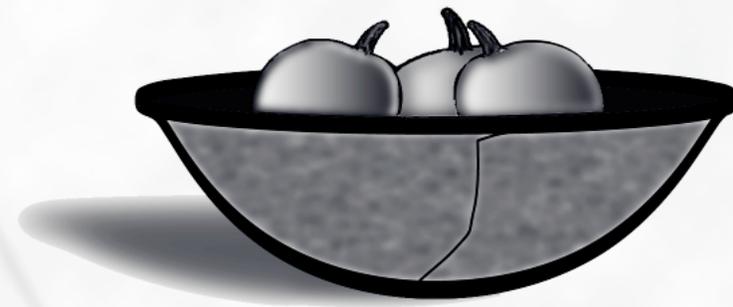
Any change in ability to breathe is going to affect your lifestyle. It may mean using a wheelchair, walking shorter distances or resting more. Portable tanks can be used when going out and oxygen concentrators can be used at home. These come with long tubing so that your freedom to move about is not limited. Blood transfusions may also help reduce shortness of breath.

Again, public image may affect your decision. As you will so many times, you must weigh the importance of what you want to do against the importance of appearances. Many people walk tall and have fun, even with an oxygen tank in tow.

*Love is like a bowl
so when you break it
glue it together*

*if it won't hold water
fill it with apples*

— John Knoepfle



NAUSEA AND LOSS OF APPETITE

As cancer progresses, your body wages an escalating battle. The side effects of the effort may mean fever, achyness, “the blahs,” and lack of interest in food. These symptoms may be caused by medication. If so, changing medication could solve the problem.

Loss of appetite and increased nausea may also mean that the cancer is overwhelming the body’s ability to process food.

Whether medicine or cancer is causing the problem, talk to your doctor.

Palliative measures

Good nutrition is important in dealing with illness. If large meals do not appeal to you, try several small meals or snacks during the day. Milk shakes, smoothies with protein powder or yogurt, trail mixes or health food bars and drinks may provide better nutrition and be easier for your body to handle than steak or bacon and eggs. You can make these snacks at home or buy them ready-to-eat.

Sometimes lack of interest in food is a side effect of lethargy. You are just too tired to be hungry. At those times, a simple snack may perk up both your energy and your spirits. Or, you may need to deal with tiredness by using oxygen or getting a blood transfusion.

Some foods, such as ginger, can lessen nausea. Ginger snap cookies, made with real ginger, are good to have on hand at home or while traveling. On the other hand, the mere smell of food may provoke nausea, as may the sight of a table or plate heaped high with food.

Both you and your caregiver must remember that loss of appetite is normal. Food should be available but *you should not force yourself to eat.*

Doctors can prescribe effective nausea medications in many forms, from suppositories to fast-acting gels that are rubbed onto your arm. These may be taken as needed or on a regular basis to prevent nausea.

A gel, called BDR, can be made of 50 mg. Benedryl (an antihistamine),

4 mg. of Decadron (a steroid) and 40 mg. of Reglan (an antiemetic). The three medicines are compounded into a topical gel or suppositories. The combination is effective and fast-acting for many people. The gel is portable and easy to use. It can be taken anywhere and discreetly applied where and when needed.

Insurance may not pay for BDR because it has not been approved in this form. Your doctor can prescribe each component separately and instruct the pharmacist to mix them.

Lifestyle considerations

Instead of scheduling three big meals each day, it may be better to eat several small meals. That may require taking food along on trips or visits.

Small containers of applesauce, pudding and cheese-and-cracker snacks are available at most supermarkets, usually in the section for school lunches. Trail mix, nuts or health bars can be stashed in the glove compartment or “survival” bag in the car. Your survival bag should also have ginger cookies and anti-nausea medicine, along with your pain medicine.

When you eat out, you and your partner may decide to split one entrée instead of ordering two full meals. Sometimes an appetizer makes a meal.

Or you can take part of the meal home for an easy lunch the next day.

If you don't feel like eating at all, you may want to set a timer to remind you to eat something, even if it is only a snack or glass of juice. This may prevent missing meals due to tiredness or lethargy. Having something to eat, however small, may restore your energy and even make you ready to eat something more substantial.

Simple foods may be more appealing and easier to digest than spicy or fatty foods. They may also be easier for your caregiver to prepare. Don't try to live up to other people's expectation. Friends may want to show their affection by preparing your once-favorite foods. Explain that your tastes have changed: Forcing yourself to eat what your body does not want will cause nausea and vomiting.

To prevent nausea, take smaller portions on a small plate. If the sight of food makes you nauseated, look at a picture on the wall or leave the table until the feeling passes. Get a prescription for anti-nausea medication, such as the gel. Take the medication with you wherever you go, especially when you go out to eat.

Remember, eat what you want, when you want it.

HOSPICE

To many, hospice sounds like the place you go when you can no longer function, when you are bedridden and within days of death.

Not so.

Hospice is a service designed to maintain the highest possible quality of life for you, keep you in your home and ease the burdens carried by both you and your caregiver.

Calling hospice is not a sign of giving up; it is a sign that you want to make informed decisions about your care. It is an acknowledgment that help is needed to deal with the effects of your disease on your lifestyle and your family.

Many people contact hospice while they still are able to work, travel and enjoy other activities. The hospice staff can offer advice and equipment to maintain your quality of life, as well as offer spiritual and emotional support.

Hospice provides nurses, social workers, physical therapists, health aides, chaplains and time off for caregivers. They help with many problems, from making a will to getting a wheelchair, from easing the side effects of medicine to getting medicine delivered to your home, from administering medicine to giving you a foot massage.

Many communities have hospice programs that cooperate with each other. When you travel, hospice may be able to arrange a wheelchair or emergency contacts at your destination.

Hospice staff and volunteers relieve you and your family of the little things that become tiring and time-wasting tasks, such as driving to the pharmacy or getting approval for medical equipment. The hospice staff can answer questions about the side effects of medicine, suggest solutions and help you make decisions about legal and medical issues before problems arise.

It is your life, to the last moment.

Live it the way you want to.

An occupational therapist may suggest changes in your home that make independence easier, such as grab bars in the shower or tools to help you put on shoes and socks. The therapist may notice obstacles, such as throw rugs and tripping hazards. These changes may prevent a fall and broken bones that could severely reduce your quality of life.

Because hospice deals constantly with many of the symptoms and problems you are experiencing, the staff has come up with creative solutions and will brainstorm new ones with you. Whether you use the suggestions is up to you. Hospice also benefits caregivers and family members. Nurses and social workers will help them understand your medications and the kind of help you really need.

Some doctors are slow to refer patients to hospice, perhaps because doing so is an admission that a cure

is not forthcoming or because they feel that the hope of a long life or a cure is psychologically valuable to patients.

Hope is important; so is having all the tools you need to maintain your quality of life.

Ask for a referral or call hospice yourself. Then you will have the information you need to decide if and when you want the extra help.

The most immediate benefit of hospice is help with the lifestyle changes discussed in the previous sections: wheelchairs; medication for nausea; tools to help when muscle tone and range-of-motion lessen; pain control techniques, from medication delivery systems to visualization; and creative solutions to individual problems.

With the experience and support of hospice staff, the last months of life can be active, enriching and enjoyable.

It is your life, to the last moment.
Live it the way you want to.

RESOURCES

Books

- *Morrie: In His Own Words*, by Morrie Schwartz, Walker and Company 1996
- *How We Die*, by Sherwin B. Nuland, M.D., Alfred A. Knopf, 1994
- *Going the Distance*, by George Sheehan, M.D., Villard Books, 1996

Internet

Many organizations provide information about treatments, both conventional and alternative; clinical trials; financial assistance and insurance issues; and coping with cancer. Among them are:

- American Cancer Society 1.800.ACS.2345 / www.cancer.org
- Cancer Care, 1.800.813.HOPE / www.cancercareinc.org
- National Cancer Institute 1.800.4CANCER / www.cancernet.nci.nih.gov

Other Internet sources of information and inspiration are:

- www.psa-rising.com
- www.prostatepointers.org
- www.cancerfacts.com

These are, of course, just a few of the many resources at your disposal. They are included because we found them particularly helpful. Talk to people, go online, browse a bookstore – find the support and information that works for you.

For additional free copies of this booklet, please contact Rotary Clubs of District 5190, 11250 Rosemary Drive, Auburn, CA 95603 or Molly Sugarman at msugarman@jps.net / 530.823.0184.



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