

*Circle Of Life: Cancer Education and Wellness
for American Indian and Alaska Native Communities*



American Cancer Society Circle Of LifeSM
Cancer Education and Wellness for American Indian and Alaska Native Communities

Wellness along the Cancer Journey:
Caregiving
Revised October 2015

Chapter 6: The Treatment Timeline



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The Treatment Timeline

Group Discussion			
	True	False	Not Sure
1. Delays in cancer treatment are not possible.			
2. Once treatment stops the patient will still need help.			

One of the first steps after being told someone has cancer will be learning about the diagnosis. This will help the caregiver and other family members understand the disease process and get an idea of what lies ahead. Some of the first questions that should be asked are:

- What kind of cancer is it?
- Where is it? Has it spread beyond where it started?
- What are the treatment options? Which do you recommend?
- What is the goal of this treatment?
- How long will treatment last? What will it be like? Where will the treatment be given?
- What side effects should we expect?
- How will treatment affect everyday activities?
- What is the likely long-term outcome? What can we expect?

When a person has cancer, there are many ways it can go. While there is no way to know for sure, the health care team should be able to give an idea of how things are likely to go. This will become clearer over time and as they get to know the person with cancer better. Just a few possible scenarios are:

- Diagnosis, active treatment, finish treatment, then survivorship with a normal life

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- Diagnosis, active treatment, finish treatment, then survivorship with possible long-term treatment effects
- Diagnosis, active treatment, finish treatment, cancer comes back (recurrence), active treatment, survivorship with ongoing treatment and ongoing treatment effects
- Diagnosis, active treatment, recurrence, survivorship with possible long-term treatment effects, another recurrence, end of life
- Diagnosis, active treatment, end of life
- Diagnosis of late-stage cancer, palliative (comfort) treatment only, end of life

Again, there are many ways that cancer can go. And things can change at any time, for better or for worse. While it would be great to know what to expect, there is no way to predict how someone will do.

Test Results

In most cases, the only way to know for sure whether a tumor or mass is cancer is for the health care provider to do a biopsy. This is when all or part of the lump is taken out with surgery and looked at under a microscope to see if there are cancer cells in it. A biopsy can also be done using a needle to take a small part of the lump. In the case of changes in blood counts, a bone marrow biopsy may be done. This is when a health care provider or nurse uses a needle to take out some of the liquid bone marrow that is inside the bones. It is checked for cancer cells. The type of biopsy depends on the size and location of the lump or the area that has changed.

Sometimes it can take awhile to get back test results. This can be a difficult time for the patient as well as for loved ones who know it might be cancer. Some notice that they think of worst-case scenarios and wonder if they will lose their loved one. Others may try to go through their days as normally as possible and not think about it. Most people have a mixture of dread and hope as they wait for the test results. It is important to know that it is normal to have these feelings. Some people find comfort in talking with other people about what's going on,

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while others wish to keep it very private. Try to respect the patient's wishes during this time.

Treatment Delays

Planning cancer treatment takes time. Most people want to start treatment right away. They worry that extra time taken to do tests or make decisions will take up precious time that could be spent fighting the cancer.

Cancer treatment should start very soon after diagnosis, but for most cancers there is no harm in waiting a few weeks to begin treatment. This gives the person with cancer time to talk about all their treatment options with the health care team, family, and friends, and then decide what's best for them.

The patient may also want to get a second opinion on what is the best treatment. This is often a good idea, especially if the patient can see a health care provider with a lot of experience in treating their type of cancer. A second opinion can give the person with cancer more information and help them feel more confident about choosing a treatment plan. Some insurance companies even require a second opinion before they will agree to pay for certain treatments. And almost all will pay for a second opinion. Still, it's a good idea to check the patient's health insurance coverage first.

The patient also may want or need time to prepare to put their normal activities "on hold" while getting treatment. For instance, arrangements for work or childcare may be needed, and taking care of these things ahead of time can help the patient better focus on dealing with treatment. Please see Appendix F for information called *Helping Children When a Family Member Has Cancer: Dealing With Diagnosis*.

Uncertainty

When a person has cancer, they go through different stages. There will be times when the caregiver and the patient do not know what will happen next. With an illness as serious as cancer, this can be scary. But there are no guarantees in cancer care. There is no way to know for sure whether the treatment will work. No one can predict the side effects or problems someone will have during

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treatment. And even after successful treatment, there is still the possibility that cancer will come back – there can even be a new, different cancer sometime in the future.

It can be hard for everyone to deal with a constant state of “not knowing.” Here are some ideas that have helped others deal with uncertainty and fear and feel more hopeful:

- Try to let go of fears, but not deny them. It is normal for these thoughts to enter a person’s mind, but it does not help to keep thinking about them over and over again. Letting them go can free a person from wasting time and energy on needless worry. Some people picture them floating away, or being vaporized. Others turn them over to a higher power to handle.
- Express feelings of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions helps many people feel less worried. People have found that when they talk about strong feelings, like fear, they are more able to manage or let go of these feelings. Thinking and talking about feelings can be hard.
- Focus energy on wellness and what can be done now to stay as healthy as possible. Find ways to relax. Make time for regular exercise, and be as active as possible.

Control what can be controlled. Some people say that putting their lives back in order makes them feel less fearful. Being involved in the patient’s health care, keeping life as normal as possible, and making lifestyle changes are just a few of the things that can be done. Even setting a daily schedule can give the caregiver more confidence and ease. And while no one can control every thought, some say they’ve resolved not to dwell on the fearful ones.

Adjusting to the Diagnosis

With time, the patient and loved ones will find out about and start to adjust to the cancer diagnosis. This is a time of change and action – everyone is getting used to the unexpected and scary situation that they now find themselves in. Even with all the activity, some people go through their days feeling numb and

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disengaged. Others may be sad, edgy, or angry. Emotions may change from minute to minute for everyone. Things may not feel settled for a long time, but there are appointments to keep, things to discuss, and plans to make.

It's important to get accurate, reliable information in writing so that the patient and caregiver are ready when questions must be asked or care coordinated:

- What is the exact name and location of the cancer?
- What is the stage of the cancer?
- What treatments are recommended? How are they done, and how long do they take?
- Will the patient need to be in the hospital? When and for how long?

Treatment for Cancer

Cancer treatment varies a lot depending on the kind and stage of cancer the patient has. The most common treatments for cancer involve surgery, chemotherapy, and/or radiation. So someone's treatment may involve time in the hospital or making many trips to a clinic for radiation or chemotherapy. The person with cancer may need more than one type of treatment, and each type comes with its own challenges.

A caregiver will want to be sure that they understand the treatment options chosen by the patient and health care provider, since they will likely be helping to plan how to make it happen. For some treatments, the patient may be able to go on their own. For others, someone may need to drive the patient or go along. In some cases, the person will get medicines that make them sleepy, or cause symptoms that will require help from others.

If the person gets chemotherapy, there may be nausea, extreme tiredness, easy bleeding, and infections to worry about. Depending on the treatment, there may be many other side effects, too. Treatment can be long or fairly short, but even short treatments tend to disrupt a person's life for several weeks. A caregiver may find that they need to take time off from work to help care for the patient. During

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treatment, they will want to learn about general cancer information, treatment effects, and how to manage side effects.

Some questions the caregiver may want to discuss with the cancer team ahead of time are:

- What symptoms do we need to tell you about right away? Which ones can wait?
- How do we reach you after office hours? On weekends? Holidays?
- What can we do to manage side effects?
- How will we know if treatment is working?

When Treatment Ends

After treatment the patient goes into a stage of healing and recovery. Less time is spent in the clinic and they will see the cancer care team less often. Patient distress may go down, but caregiver stress may not. Day-to-day care for and monitoring of the patient becomes the caregiver's job, and not seeing the cancer care team as often may leave a caregiver feeling alone and without back-up or support.

A caregiver may want to ask the health care provider these kinds of questions, and write down the answers for later:

- What kind of follow-up visits are needed? How often and for how long?
- Are there any symptoms that we should let you know about? Who should we call for other problems?
- When will the patient be able to go back to a regular work schedule (if they have been off work or working fewer hours)?
- How will we know if the cancer has come back?

After treatment is over, be sure that the patient has copies of their cancer treatment information. They will need to keep these records for the rest of their lives:

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- Summary of the person's exact diagnosis and cancer stage
- Treatments used (including all medicines and doses)
- Summary of surgery (if one was done)
- Biopsy or pathology reports
- Radiation treatment and dose records
- Discharge reports from any stays in the hospital
- Records of any major problems or complications during treatment

The patient may need to go to different places to get these records. For instance, the hospital medical records department will usually have hospital discharge and surgical reports. If radiation or chemo was done on an outpatient basis, the health care provider who coordinated the treatment can explain how to get the reports. The patient may need to ask the surgeon where to get copies of pathology reports.

It is important that these records be collected soon after treatment. Clinics and hospitals destroy records after a few years, and the only copies may be the ones the patient has.

After all this information is collected, the caregiver may want to keep copies as well. These records are important in the event that questions come up later, the patient needs to see a different health care provider in the future, or if the cancer comes back.

Going Back to Work or Normal Activity

As curative treatment winds down and the healthcare provider checks the patient for any remaining signs of cancer, the patient may be given the "all clear" to go back to work. Or it may be that a loved one needs to slowly increase their work duties; this will depend on their physical condition and the type of job they have.

The caregiver may need to help get the notes from the health care provider that will be needed to clear the patient for full work duties when the time comes. But when a loved one starts working a more normal schedule, there may be days of fatigue in which the caregiver's help will still be needed. It may take some time to

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get past this phase. So the caregiver may still need a circle of helpers so that they too, can start getting back to a more normal schedule.

If the fatigue continues, the patient may need to go back to the health care provider to see if there is a new problem or if there is anything more they can do to help. This may be a time where the Americans with Disabilities Act can be helpful to some patients. It can be used to negotiate for special equipment or a different work schedule. See Appendix G for more information about the Americans With Disabilities Act.

It is possible that life-saving treatments affect the patient in ways that will not go away. For some people, long-term effects mean permanent life changes, so that they cannot go back to the life they had before treatment. It is normal for the patient and sometimes loved ones to grieve the patient's loss of whatever they might have lost due to treatment. Accepting these losses can take time for both the patient and caregiver.

The caregiver may find themselves continuing to do the things they did when the patient was in treatment. But it is important that, over time, the caregiver let the patient go back to doing the things they can and should do on their own. This may take place over a period of months as the patient gets stronger. Check in every week or two to see what they are doing and can start doing, either alone with a little help. If there are things that the patient can't quite do, the caregiver can talk with the health care provider about a referral to a physical therapist or occupational therapist. These professionals may be able to help the patient improve their abilities by helping build muscle strength and/or offering assistive devices.

When Cancer Returns

Sometimes there is no evidence of cancer when treatment is finished, but the cancer still comes back. In that case, it helps to find out whether there is hope for a cure, what kind of treatment the health care provider recommends, and what the goals of this treatment are.

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It may be that the cancer is not curable, but that treatment may prolong life. If that is the case, the patient may want to know the pros and cons of getting more treatment and of not getting treatment. For instance, if treatment can stop the cancer and is likely to prolong survival for several years, it may be worthwhile even if there will be serious side effects every few weeks. On the other hand, if treatment is expected to prolong life for four to six months and cause troublesome side effects, the patient might choose palliative (comfort) care rather than active treatment. Talk over the expected effects and outcomes of getting treatment versus not getting treatment to be sure the situation is well understood. The caregiver needs to be sure about what is being asked of them if further treatment is given.

Ongoing Treatment

Sometimes treatment doesn't come to an end at the expected time. In some cases, cancer becomes a chronic illness – a disease that people can live with and manage on a day-to-day basis over a long time, much like diabetes or heart disease. The person with cancer may decide to continue treatment as long as it slows down or stops cancer growth, even if a cure is no longer possible.

Caring for someone getting ongoing treatment is more complex. More and more often treatments are managed as an outpatient or even given at home. This means more responsibilities for the caregiver. And as time goes on, the people who were there to help may need to limit the time they spend helping the patient. This can be a very demanding situation for a caregiver. The caregiver is helping the patient as they get treatment, so there are ongoing side effects and frequent appointments to deal with. The difference is that this time, it is not known how long this will last. Living with this uncertainty can be an extra challenge.

Some patients are able to go back to work during this period of ongoing treatment. They may need extra help only for a few hours or days after each treatment. They may also need help with home responsibilities, family, and bills. In other cases, less frequent chemo treatments and better management of side effects mean that the caregiver can work a more normal schedule during long-term treatment. In some cases, both the patient and caregiver go back to outside

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jobs. Still, chemo or other treatments usually mean that some schedule changes will be needed.

Even if everyone goes back to their jobs, someone will still need to keep up with the treatment plan, the medical records, and the bills. This can be demanding for the patient and caregiver. They may both need support with the amount of work that is needed on top of working and dealing with cancer. And emotional support may be needed to help the patient, caregiver, and other family members cope with knowing that the cancer cannot be cured.

When Treatment Stops

If treatment is no longer helping and the cancer is still growing, a patient may decide to stop treatment. They may choose to get care that only helps with symptoms. It helps if the patient can put into words and share what is most important to them with others who are close to the person. The patient will have to decide things like, “When do I stop trying to beat the cancer and enjoy the rest of my life?” or “Would I rather spend the next two months reading and playing with my grandchildren or dealing with side effects?”

Sometimes, caregivers can help patients clarify their highest priorities so that they can focus on them before the chance is lost. Other times, it may take someone on the treatment team or a mental health professional to help the patient clarify what is most important to them, and what can be expected from further treatment. This is a difficult time for everyone, and help from the medical team may be needed to fully understand the situation and figure out what is best for the patient.

Once the decision to stop curative treatment has been made, make sure that other family members and loved ones understand and can support the patient’s decision. It is now time for another family meeting, where questions can be answered and concerns addressed. Be sure that other day-to-day caregivers are invited, if they are still involved in the patient’s care.

It is also time to talk with the health care provider about palliative care. There are many things that can be done to manage the symptoms of cancer, such as pain,

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trouble breathing, and fatigue. When these symptoms are relieved, the patient may have more energy to spend time doing those things that they value most. The caregiver will want to be in close contact with the health care provider to be sure that any new symptoms are quickly addressed.

If the patient is expected to live only a few months, hospice may be a good option. Hospice is intended to relieve discomfort and make the patient better able to enjoy the time they have. In most cases, hospice is given at home and requires that the patient have a primary caregiver. Having hospice staff on call 24/7 can make it easier for the caregiver to know whom to call when the patient has a new problem or a symptom that is not relieved. Hospice also provides emotional and spiritual support for the family and caregiver during this transition. The caregiver may wish to talk with the hospice nurse or chaplain about coming to a family meeting to talk about the new goals of care and how they will work with them. Again, it is helpful if the patient is able to attend.

As the caregiver works with the patient and helps make the most of the rest of their life, it is normal to feel sad and even start to grieve. A caregiver will want to continue their circle of support. A support group or mental health professional may also help during this time.

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Activity

Please use the simple table to begin thinking about financial matters that should be tracked. One tip is to keep a file of bills and EOBs to make notes on them.

	Monthly Expenses	Insurance Claims	Medical Visit Co-pays	Medication Co-pays
January				
February				
March				
April				
May				
June				
July				
August				
September				
November				
December				

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Story of Hope

“No question is too small or too silly to ask. I never was afraid to call the doctor or staff with questions about anything even questions about our bills and insurance. I found that our doctor and his staff were willing to answer any question.”

– Judith, husband’s caregiver

Key Messages

- Cancer treatment should start very soon after diagnosis, but for most cancers, there is no harm in waiting a few weeks to begin treatment. Sometimes it is not possible to start treatment right away.
- Cancer treatment varies a lot depending on the kind and stage of cancer the patient has. Explore all of the options that are available and make sense.
- After treatment is over, be sure that the patient has a written summary of their diagnosis, treatments used, and other important medical information. This is very important for health care after treatment.
- When a loved one starts working a more normal schedule after treatment, there may be days of fatigue in which the caregiver’s help will still be needed. Please remember to take care of yourself.