Temodar® and Brain Tumors – Helpful Hints

We have designed this handout to serve as a resource for you while you are taking Temodar®, also known as temozolomide. It will explain how it is taken, side effects you may have, and how to deal with side effects.

**What is Temodar® and how will I get it?**

- It is a chemotherapy drug given as a pill. Chemotherapy is a group of drugs used to fight cancer. It affects cells that grow quickly, but it can also affect some of your normal cells.

- You will take the medicine either daily with radiation or for 5 days every month. Your doctor will instruct you on when to take it.

- You will see your doctor midway through radiation treatment, so he or she can check your blood tests and examine you.

- Once you’ve completed radiation, or if you are taking Temodar® without radiation, you will see the doctor monthly. You will have lab work done before each visit. Your doctor will also prescribe the next round of Temodar® at this visit. Some of these visits involve an MRI scan of your head to check the tumor. This is called the maintenance phase.

**How do I take the Temodar®?**

- When Temodar® is taken along with radiation, it is given daily (at a lower dose). Once the treatments are finished, you will change to taking Temodar® five days a month.

- After radiation therapy or the maintenance phase, you will take the medicine for five (5) days in a row. That means that there will be three weeks in each month where you will not take the medicine.

- If you are on a clinical trial or have recurrence of your tumor, you may have a different schedule. Your doctor will tell you how to take your Temodar®.

There are very specific instructions about how and when to take Temodar®.

- You should always take Temodar® right before you go to bed, unless directed otherwise.
• It should be taken on an empty stomach. This means you shouldn’t eat anything for two hours before and an hour after you take it. You can drink water during this time. Just no “food.”

• It is important **not** to open or split the capsules. Temodar® should be swallowed whole with water. **Never** chew the capsules.

• One hour before taking it you should take your anti-nausea medicine. We may also instruct you to take the anti-nausea medicine the next morning.

• If you take “bedtime” medicines, these can be taken with the anti-nausea medicine. They should **not** be taken with the Temodar®.

• You will be given a calendar that will describe what time of the day and which days to take the Temodar®. It will also tell you when to take the anti-nausea medicine.

• If you miss a dose, contact your doctor or nurse. **Do not make up the missed dose by taking a double dose.**

• If you or your family should touch a pill, or a pill accidently breaks, you **must** wash your hands with soap and water right away.

**What are the side effects?**

• The side effects you have depend on your health, your body, and how you respond.
• Some people have very few side effects, but others have more.
• These are only things to watch for. **It does not** mean that you will have all of these side effects.
• It is important to let your health care team know about any problems you are having. There are many things that can be done to help you.

**What are the major side effects of Temodar®?**

• **Nausea** – You have been given an anti-nausea medicine. It is very important that you take it as prescribed. If it is taken as ordered, it is **rare** for people to have nausea and vomiting. Sometimes, people say they feel “funny” or “have a slightly upset stomach” the first few days. This feeling often lessens by the end of the cycle. It occurs less often the more cycles you take of the Temodar®. Again, everyone does not respond the same way. If you have symptoms that are not controlled with the medicines, ask your doctor or nurse for advice.

Food may taste “funny” or you may not be as hungry for a few days during or after your treatment. This is okay. It is not okay if you can’t keep liquids down. **Be sure to call your doctor or nurse if you are not able to drink water or other fluids.**
It only takes 20 minutes to absorb the Temodar® on an empty stomach. If nausea happens, it most often occurs a few hours after taking it. If you vomit within half an hour (30 minutes) of taking Temodar®, tell your doctor by calling the next day. Do not take another dose.

• **Constipation** – You will receive handouts that discuss how to treat and prevent constipation. **Constipation is a major concern while taking Temodar®.** We suggest you have a laxative and stool softener in the house in case you need one.

Many people have mild constipation while taking Temodar® with radiation. The major time for concern is the week you are taking it during the maintenance phase and for a few days afterward. This is due to the higher dose of Temodar®.

If you have constipation during radiation or during any monthly cycle of Temodar®, we suggest you begin a bowel program a few days before starting each cycle. Follow this program for a few days after each cycle.

If you are someone who has problems with constipation or irregular bowel patterns, we suggest you begin a bowel program now. Keep doing it during the entire course of radiation and monthly while you are taking the Temodar®.

If your stool becomes firmer or hard, start a stool softener. If you don’t have a bowel movement, begin laxatives. See the provided handouts for suggestions and choices. **Reminder:** we want you to have daily bowel movements.

Your nurse or doctor will discuss with you what a bowel program is. They will help set one up that will work for you. If your program isn’t as effective as you would like or need, please discuss this with them so it can be changed.

• **Fatigue** – Many patients find they are able to carry on a normal routine while taking Temodar®. If fatigue occurs, it most often occurs during radiation or near the end of the treatment cycle and a few days after. Many people find that moderate exercise, frequent smaller meals, and regular sleep and rest periods can help relieve fatigue. If the fatigue becomes a bother or is stopping you from doing the things you are used to doing, discuss your concerns with your doctor or nurse. We have suggestions and handouts to help you deal with fatigue.

• **Lower blood counts** – While you are on Temodar® you are at a greater risk of getting infections and bleeding. This is because of the drug’s effect on your white blood cells and platelets. In very rare cases blood counts can drop very low and require blood or platelet transfusions, and in some cases may be life threatening.

To watch for this, you will have blood drawn weekly during radiation and monthly on the maintenance phase. We will be watching your blood tests closely and will let you know if there are any concerns. If you are taking Temodar® 5 days out of the month, the blood count may decrease about 3-4 weeks after taking the drug. If you are taking it daily with
radiation, this decrease may occur between weeks 3 and 6 of your treatments. **You will always have blood drawn the day before or the same day you come to see the doctor.**

If you need dental work or surgery, please let your doctor know. A lowered white cell count will increase your chance of getting an infection. A low platelet count puts you at risk for bleeding.

Taking Temodar can increase your long-term risk of developing leukemia. This is extremely rare, but if it does occur it would likely be years after the drug is used. Your doctor feels the risk of what might happen outweighs the risk of what will happen if you do not get the drug.

- **Headache** – Headaches are a very rare side effect. If you have a severe headache while on Temodar®, it is most likely not caused by the Temodar®. It may be a sign of brain edema or swelling. Be sure to discuss these headaches with your doctor. She or he may prescribe something to treat them. We suggest you use Tylenol®. **Do not** use ibuprofen or aspirin.

- **Rash** – Rarely, some people taking Temodar® get a rash. This occurs more often if you are not taking a steroid (dexamethasone). The rash from Temodar® usually occurs on the chest and covers the chest or belly. Although not a direct side effect of Temodar®, people who take Temodar® are at risk of developing shingles. This is because their immune system has been affected. See the note below about Shingles. If you notice a rash, please tell your doctor.

  - **Shingles**: Any person who has had chicken pox can have shingles. The rash from shingles results in a group of blisters in a pattern (mostly a line) that follows the nerve along that area of skin. Most often, shingles is on one side of the body. The skin lesions can occur any place on the body, although the most common place is on the trunk.
  - Pictures of the rash from shingles are available on-line for you to review. If you don’t have access to the internet, please ask your doctor or nurse to show you pictures.
  - If you think you have shingles you need to seek medical attention right away.

- **Hair Loss** – Hair loss is very rare with this treatment. If you are taking Temodar® along with other chemotherapy or radiation, there may be hair loss. It is most often due to one of those treatments.

- **Thrush** – Although thrush is not a side effect of Temodar®, people who have lowered blood counts or who are taking steroids can develop thrush. Thrush is a yeast infection that occurs in the mouth. You should inspect your tongue and the inside of your mouth daily. It should be pink and smooth. If you notice any red or white patches on your tongue or develop a “funny or strange” taste in your mouth, please let your doctor or nurse know.
• **Sexuality and Fertility** – Temodar® should have no effect on sex drive. You should be able to have sexual relations with your partner. Temodar® can cause birth defects. Birth control must be used while you are taking it. You need to keep using birth control for a minimum of six months after treatment stops. Females should avoid getting pregnant while on Temodar and for a minimum of six months after stopping Temodar. Women should not breastfeed while taking this drug. Males may want to consult your doctor about banking your sperm before treatment.

If your platelets or white blood cells are low, you may need to avoid intercourse until blood counts return to normal. We will let you know if this is a concern.

Talk with your partner about how the treatment and having a brain tumor affects you. You may have changes in sexual desire during this time.

• **Brain Swelling/Brain Edema** – Brain edema is “extra fluid” within the tissues of the brain. This fluid can occur as a result of tumor cell growth, tumor cell death, or as a side effect of treatment. Since the skull is a rigid “container” with no extra room, this fluid causes pressure on the brain, blood vessels, and nerves. This results in the person having symptoms. If you notice these symptoms, please discuss them with your doctor.

**What are the signs of brain edema?**
- Increasing or severe headaches that are not relieved by Tylenol®
- Headaches that occur daily or several times a day, even if relieved by Tylenol®
- Headaches with nausea and vomiting
- Nausea or vomiting
- Any change in strength or sensation (numbness or tingling)
- Clumsiness or coordination difficulty of a hand or leg
- Vision, hearing, or speech changes or problems
- Balance or walking problems or dizziness
- New onset of confusion
- New seizures or worsening of dizziness

• **Use with other medicines** – Temodar® most likely will not react with any other medicines you take. You should not add any new medicines while taking the Temodar® unless you discuss them with your doctor. Make sure your doctor and pharmacist know all the things you are taking. Be sure you tell your doctor about any herbal supplements or vitamins, too. Herbal supplements and vitamins need to be considered medicines. Many times we do not know the interactions between herbal supplements, vitamins, and Temodar®. It is important you list them each time you are asked about your medicines.

Please make a list of your medicines and how much of each you are taking. Bring this list with you to each doctor visit. This prevents you and your doctors from “guessing” how much you are taking. It also allows the doctor to adjust your doses.
We ask that you bring in the pill bottles for each visit. Do not leave them in the car. We want to look at the bottles of medicines you are taking. This includes the bottle for the Temodar® and the anti-nausea medicine, even if they are empty.

If you have new or changing symptoms while taking the Temodar® tell your doctor or nurse about them.

• **Other things to consider:**

  While taking Temodar® you should avoid alcohol.

  You should not be driving during this time.

**How will I pay for Temodar® treatment?**

Many insurers, including Medicare, will cover the cost of it. If you have financial need beyond what insurance covers, the manufacturer of Temodar® has a “Commitment to Care” program. This service can help you find other sources of reimbursement. You can contact them by calling 1-800-521-7157.

The pharmacists at the UW are here to help, and may have more resources. Please discuss your medicine concerns with them as well.

If you have financial, insurance, or work related concerns beyond medicines, please ask your doctor or nurse to set up an appointment for you to meet with a social worker.

**Other Resources**

There are many groups that help people with brain tumors cope with their diagnosis. They can also be very good sources of information. A few of them are listed below.

**American Brain Tumor Association**
1-800-886-2282  
[www.abta.org](http://www.abta.org)

**American Cancer Society**
1-800-ACS-2345  
[www.cancer.org](http://www.cancer.org)

**National Brain Tumor Society**
1-800-934-CURE  
[www.braintumor.org](http://www.braintumor.org)
The UW Comprehensive Cancer Center also offers

Adult Brain Tumor Support Group.
Ask your nurse to learn more about this group. It meets the 3rd Tuesday of the month at the UW hospital.

What happens if I have questions or problems?

While you are having treatments you will see your doctor or nurse monthly. If you have any questions at any time between visits, please contact your doctor or nurse. If you receive radiation, you will be seeing a doctor weekly.

If you need help after hours or on weekends call 608-262-0486. This is the paging operator.

- If you are receiving radiotherapy (radiation) along with your Temodar® ask for the Radiation Oncology resident on call.

- If you are receiving Temodar® alone (no radiation) ask for the Oncology resident on call. Tell them you are a patient of Dr. ________________.

Give the operator your name and phone number with the area code. The doctor will call you back.

If you live outside of the area, you can call toll-free 1-800-323-8942 for the paging operator.

Don’t forget

• Bring all your pill bottles. This includes the empty Temodar® and anti-nausea medicine bottles. Do not leave them in the car. The doctor will want to look at all of the bottles. This includes any bottles of herbal and vitamin supplements.

• Constipation is a major concern. You need to make sure to follow your bowel program. Have all the medicines you need in the house to begin the bowel program when needed and a few days before each Temodar® cycle if you have constipation during any treatment cycle.

• We are here to help. If you have questions or concerns, please contact us.