Early Detection, Diagnosis, and Staging of Ewing Tumors

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Ewing Tumors Be Found Early?
- Signs and Symptoms of Ewing Tumors
- How Are Ewing Tumors Diagnosed?

Stages and Outlook (Prognosis)

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- How Are Ewing Tumors Staged?
- Survival Rates for Ewing Tumors by Stage

Questions to Ask About Ewing Tumors

Here are some questions you can ask your cancer care team to help you better understand your cancer diagnosis and treatment options.

- What Should You Ask the Doctor About Ewing Tumors?

Can Ewing Tumors Be Found Early?

Ewing tumors are uncommon, and there are no widely recommended screening tests for these tumors. (Screening is testing for cancer in people without any symptoms.) Still,
Ewing tumors often cause symptoms that allow them to be found early (before they have clearly spread to other parts of the body).

The most common symptom of a Ewing tumor is pain in the area of the tumor. Sometimes the tumor shows up as a lump or swelling on an arm, leg, or the trunk. Sometimes the lump feels warmer than the rest of the body, and sometimes the child has other symptoms like a fever or not feeling well.

Of course, children and teens often get sore or have lumps and bumps from normal activities. But pains or lumps that don’t go away should be checked by a doctor. The same is true if a lump feels warm and/or the child has a fever. These symptoms are more likely to have other causes, such as an infection, but they need to be checked by a doctor so that the cause can be found and treated, if needed.

- References
  See all references for Ewing Family of Tumors

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Signs and Symptoms of Ewing Tumors

Ewing tumors are often found because of the symptoms they cause.

**Pain**

Most children and teens with Ewing tumors will have pain in the area of the tumor. Bone pain can be caused by the tumor spreading under the outer covering of the bone (periosteum), or the pain can be from a break (fracture) in a bone that has been weakened by the tumor.

**Lump or swelling**

Over time, most Ewing bone tumors and almost all non-bone (soft tissue) Ewing tumors cause a lump or swelling, which is more likely to be noticed in tumors in the arms or
legs. The lump is often soft and feels warm. Tumors in the chest wall or pelvis (hip bones) might not be noticed until they have grown quite large.

Other symptoms

Ewing tumors can also cause other symptoms, some of which are more common in tumors that have spread:

- Fever
- Feeling tired
- Weight loss

Rarely, tumors near the spine can cause weakness, numbness, or paralysis in the arms or legs, while tumors that have spread to the lungs can cause shortness of breath.

Many of the signs and symptoms of Ewing tumors are more likely to be caused by something else. Still, if your child has any of these symptoms, see a doctor so that the cause can be found and treated, if needed.

Because many of these signs and symptoms can be confused with normal bumps and bruises or bone infections, Ewing tumors might not be recognized right away. For example, the doctor might try giving antibiotics first if an infection is suspected. The correct diagnosis might not be made until the signs and symptoms don’t go away (or get worse) and the bone is then x-rayed.

- References
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How Are Ewing Tumors Diagnosed?

Ewing tumors are usually found because of signs or symptoms a child or teen is having. If a tumor is suspected, tests will be needed to find out for sure.
Medical history and physical exam

If your child has signs or symptoms that could be from a tumor, the doctor will want to get a complete medical history to find out more about the symptoms and how long they have been present. The doctor will also do a complete physical exam, paying special attention to any areas causing pain or swelling.

If a doctor suspects the child might have a bone tumor (or another type of tumor), more tests will be done to find out. These might include imaging tests, biopsies, and/or lab tests.

Imaging tests

Imaging tests (such as x-rays, MRI scans, CT scans, bone scans, and PET scans) create pictures of the inside of the body. Imaging tests can be done for many reasons, including:

- To help find out if a suspicious area might be cancer
- To determine the extent of a tumor or learn how far a cancer may have spread
- To help determine if treatment is working

Patients who have or may have a Ewing tumor will have one or more of these tests.

X-rays

If a bone lump doesn't go away or the doctor suspects a bone tumor for some other reason, an x-ray of the area will probably be the first test done. A radiologist (doctor who specializes in reading imaging tests) can usually spot a bone tumor on an x-ray and can often tell if it is likely to be a Ewing tumor. But other imaging tests may be needed as well.

Even if an x-ray strongly suggests a Ewing bone tumor, a biopsy (described below) is still needed to confirm that it is cancer rather than some other problem, such as an infection.

Magnetic resonance imaging (MRI) scan

Often, an MRI scan is done to get a better look an abnormal area seen on an x-ray. MRI scans usually can show if it is likely to be a tumor, an infection, or some type of bone damage from other causes. MRI scans can also help determine the extent of a tumor,
as they show in detail the marrow inside bones and the muscle, fat, and connective
tissue around the tumor. Knowing the extent of the tumor is very important when
planning surgery or radiation therapy.

MRI scans might also be done to see if the cancer has spread to other areas, such as
the spine or pelvis (hip area). MRI scans can also be used during and after treatment to
see how well the tumor is responding.

MRI scans create detailed images using radio waves and strong magnets instead of x-
rays, so there is no radiation involved. A contrast material called gadolinium may be
injected into a vein before the scan to help see details better.

MRI scans may take up to an hour. Your child may have to lie on a table that slides
inside a narrow tube, which is confining and can be distressing. The test also requires a
person to stay still for several minutes at a time. Open MRI machines, which are less
confining, might be another option, but they still require staying still for long periods of
time. The machines also make buzzing and clicking noises that may be disturbing.
Sometimes, younger children are given medicine to help keep them calm or even
asleep during the test.

**Computed tomography (CT or CAT) scan**

CT scans of the chest are often used to see if a Ewing tumor has spread to the lungs.
MRI scans are usually a bit better at defining the extent of the main tumor itself, but a
CT scan of the tumor may be done as well.

The CT scan uses x-rays to make detailed cross-sectional images of parts of the body,
including soft tissues such as muscles. Instead of taking one picture, like a regular x-
ray, a CT scanner takes many pictures as it rotates around your child while he or she
lies on a table. A computer then combines these pictures into images of slices of the
part of the body being studied.

Before the scan, your child may be asked to drink a contrast solution and/or get an
intravenous (IV) injection of a contrast dye that helps better outline abnormal areas in
the body. If a contrast dye is to be injected, your child may need an IV line. The contrast
can cause some flushing (a feeling of warmth, especially in the face). Some people are
allergic and get hives. Rarely, more serious reactions like trouble breathing or low blood
pressure can occur. Be sure to tell the doctor if your child has any allergies (especially
to iodine or shellfish) or has ever had a reaction to any contrast material used for x-rays.

CT scans take longer than regular x-rays, but not as long as MRI scans. A CT scanner
Bone scan

A bone scan can help show if a cancer has metastasized (spread) to bones in other parts of the body, and might be part of the workup for a child with an Ewing tumor. This test is useful because it can show the entire skeleton at once. (A positron emission tomography [PET] scan can often provide similar information, so a bone scan might not be needed if a PET scan is done.)

For this test, a small amount of low-level radioactive material is injected into a vein (intravenously, or IV). (The amount of radioactivity used is very low and will pass out of the body within a day or so.) The substance settles in abnormal areas of bone throughout the body over the course of a couple of hours. Your child then lies on a table for about 30 minutes while a special camera detects the radioactivity and creates a picture of the skeleton. Younger children might be given medicine to help keep them calm or even asleep during the test.

Areas of active bone changes appear as “hot spots” on the skeleton because they attract the radioactivity. These areas may suggest the presence of cancer, but other bone diseases can also cause the same pattern. To be sure, other tests such as plain x-rays or MRI scans, or even a bone biopsy might be needed.

Positron emission tomography (PET) scan

For a PET scan, a form of radioactive sugar (known as fluorodeoxyglucose or FDG) is injected into the blood. The amount of radioactivity used is very low and will pass out of the body within a day or so. Because cancer cells in the body are growing quickly, they absorb large amounts of the sugar. After about an hour, your child will lie on a table in the PET scanner for about 30 minutes while a special camera creates a picture of areas of radioactivity in the body. The picture is not detailed like a CT or MRI scan, but it provides helpful information about the whole body.

PET scans can be very helpful in showing the spread of Ewing tumors and in finding out whether abnormal areas seen on other imaging tests (such as a bone scan or CT scan) are tumors. PET scans can also be repeated during treatment to monitor the cancer over time.
Some newer machines can do a PET and CT scan at the same time (PET/CT scan). This lets the doctor compare areas of higher radioactivity on the PET scan with the more detailed appearance of that area on the CT scan.

To learn more about these and other imaging tests, see our document *Imaging (Radiology) Tests*.

**Biopsy of the tumor**

The results of imaging tests might strongly suggest a Ewing tumor, but a biopsy (removing some of the tumor for viewing under a microscope and other lab testing) is the only way to be certain. A biopsy is also the best way to tell Ewing tumors from other types of cancer.

*If the tumor is in a bone, it is very important that a surgeon experienced in treating bone tumors does the biopsy.* Whenever possible, the biopsy and the surgery to treat the cancer should be planned together, and the same surgeon should do both. Proper planning of the biopsy can help prevent later complications and might reduce the amount of surgery needed later on.

There are a few ways to get a sample of the tumor to diagnose Ewing tumors.

**Excisional biopsy**

In very rare cases, if the tumor is small enough and in a good location, the surgeon can completely remove it while the child is under general anesthesia (asleep). This is called an *excisional biopsy*.

**Incisional biopsy**

In most cases of suspected Ewing tumors, an incisional biopsy (taking only a piece of the tumor) is more likely to be done. This can be done in a couple of ways:

- **Surgical (open) biopsy:** For this type of biopsy, the surgeon cuts away a piece of the tumor through an opening on the skin.
- **Needle (closed) biopsy:** In this type of biopsy, the surgeon puts a large, hollow needle through the skin and into the tumor to remove a piece of it.

Incisional biopsies are often done while the patient is under general anesthesia (in a deep sleep), but in older teens and adults they are sometimes done using sedation and
a local anesthetic (numbing medicine).

If general anesthesia is going to be used for the biopsy, the surgeon may also plan other procedures while the child is asleep to avoid having to do them as separate operations later on. For example, if the tumor is thought to have spread to the chest or elsewhere, the surgeon may take biopsy samples of these suspected tumors when the child is still asleep. The doctor might also do a bone marrow biopsy (see next section) at this time to see if the cancer has spread to the bone marrow spaces.

During the biopsy (while the child is still asleep), a pathologist (a doctor specializing in lab tests to diagnose diseases) can take a quick look at the biopsy samples under a microscope. If it looks like a Ewing tumor, the child will very likely need chemotherapy as part of treatment, so the surgeon may place a small flexible tube, known as a central venous catheter, into a large vein in the chest area during the same operation. The catheter end lies just under or outside on the skin. It can stay in place for several months during treatment. The catheter gives doctors and nurses easier access to the vein, which is allows the child to get fewer needle sticks when chemotherapy is given or blood needs to be drawn at a later time.

**Bone marrow aspiration and biopsy**

These tests are used to see if the cancer cells have spread into the bone marrow, the soft inner parts of certain bones. The tests aren't usually done to diagnose Ewing tumors, but they may be done once the diagnosis is made because it is important to know if the tumor has spread to the bone marrow.

Bone marrow aspiration and biopsy are usually done at the same time. In most cases the marrow samples are taken from the back of both of the pelvic (hip) bones.

These tests may be done during the surgery to biopsy or treat the main tumor (while the child is still under anesthesia), or they may be done as a separate procedure.

If the bone marrow aspiration is being done as a separate procedure, the child lies on a table (on his or her side or belly). The area over the hip is cleaned, and the skin and the surface of the bone are numbed with a local anesthetic, which may cause a brief stinging or burning sensation. In most cases, the child is also given other medicines to make them sleepy, or they might even be asleep during the procedure. A thin, hollow needle is then inserted into the bone, and a syringe is used to suck out a small amount of liquid bone marrow.

A bone marrow biopsy is usually done just after the aspiration. A small piece of bone
and marrow is removed with a slightly larger needle that is pushed down into the bone. Once the biopsy is done, pressure is applied to the site to help stop any bleeding.

Samples from the bone marrow are sent to a pathology lab, where they are looked at and tested for cancer cells.

**Testing biopsy samples**

A doctor called a *pathologist* looks at all biopsy specimens under a microscope to see if they contain cancer cells. If cancer is found, the specific type of cancer can often be determined as well. But because cells from Ewing tumors share many of the same features as cells from other types of childhood cancer, more lab tests are often needed.

**Immunohistochemistry**

For this test, a portion of the biopsy sample is treated with special proteins (antibodies) that attach to substances found on Ewing tumor cells but not on other cancers. Chemicals (stains) are then added so that cells containing these substances change color and can be seen under a microscope. This lets the pathologist know that the cells are from a Ewing tumor.

**Cytogenetics**

For this test, chromosomes (pieces of DNA) from the tumor cells are looked at under a microscope to detect any changes. Ewing tumor cells almost always have chromosome translocations, where 2 chromosomes swap pieces of their DNA. In most cases, the cells have translocations between chromosomes 22 and 11. Less often, the translocation is between other chromosomes. Finding these changes can help doctors tell Ewing tumors from other types of cancer. Other types of chromosome changes can also be found in some Ewing tumors.

Getting the results of cytogenetic testing usually takes about 2 to 3 weeks because the cancer cells must be grown in lab dishes for a couple of weeks before their chromosomes can be seen under the microscope.

*Fluorescence in situ hybridization* (FISH) is a type of cytogenetic test that uses special fluorescent dyes to spot specific chromosome changes in Ewing tumors. FISH can find most chromosome changes (such as translocations) that are visible under a microscope in standard cytogenetic tests, as well as some changes too small to be seen with usual cytogenetic testing.
FISH can be used to look for specific changes in chromosomes. It is very accurate and can usually provide results within a couple of days.

**Reverse transcription polymerase chain reaction (RT-PCR)**

This test is another way to find translocations in tumor cells to confirm the type of tumor. RT-PCR is a very sensitive test that is often able to detect very small numbers of cells with translocations, which wouldn’t be detected by cytogenetics.

RT-PCR is also useful in looking for leftover or recurrent cancer after treatment. For example, if RT-PCR testing of a bone marrow sample after treatment finds cells with a typical Ewing tumor translocation, it is likely that the cancer has not been cured, so more treatment is needed.

**Blood tests**

No blood test can be used to diagnose Ewing tumors. But certain [blood tests](#) may be helpful once a diagnosis has been made.

A complete blood count (CBC) measures the levels of white blood cells, red blood cells, and platelets in the blood. An abnormal CBC result at the time of diagnosis might suggest the cancer has spread to the bone marrow, where these blood cells are made.

A blood test for levels of an enzyme called *lactate dehydrogenase* (LDH) is typically done at diagnosis. A high LDH level indicates the cancer may be harder to treat.

Standard blood tests are done often to check a child’s general health both before treatment (especially before [surgery](#)) and during treatment (such as [chemotherapy](#)) to look for possible problems or side effects. These tests often include a CBC to monitor bone marrow function and blood chemistry tests to measure how well the liver and kidneys are working.

- [References](#)
  [See all references for Ewing Family of Tumors](#)

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How Are Ewing Tumors Staged?

Once a Ewing tumor has been diagnosed, tests are done to determine the stage (extent of spread) of the cancer. The stage of a Ewing tumor is one of the most important factors determining a person’s outlook (prognosis) and in choosing treatment.

The stage is based on results of imaging tests and biopsies of the main tumor and other tissues, which were described in the section “How are Ewing tumors diagnosed?”

A staging system is a standard way for the cancer care team to sum up the extent of the cancer. The formal (and more detailed) staging system for Ewing tumors is the American Joint Committee on Cancer (AJCC) system for bone cancer. It is described here to help you understand it, in case your doctor refers to it. But for treatment purposes, doctors often use a simpler system, dividing Ewing tumors into localized or metastatic groups. This is described below as well.

Staging can be confusing. If you have any questions about the stage of the cancer, ask someone on the health care team to explain it to you in a way you understand.

AJCC staging system for bone cancer

The AJCC uses one system to describe all bone cancers, including Ewing tumors that start in bone. Extraosseous Ewing (EOE) tumors (Ewing tumors that don’t start in bones) are staged differently. They are staged like soft-tissue sarcomas. Information about soft-tissue sarcoma staging can be found in Sarcoma - Adult Soft Tissue Cancer.

The AJCC staging system for bone cancers is based on 4 key pieces of information:

- **T** describes the size of the main (primary) tumor and whether it appears in different areas of the bone.
- **N** describes the extent of spread to nearby (regional) lymph nodes (small bean-sized collections of immune system cells). Bone tumors rarely spread to the lymph nodes.
- **M** indicates whether the cancer has metastasized (spread) to other organs of the body. (The most common sites of spread are to the lungs or other bones.)
- **G** stands for the grade of the tumor, which describes how the cells from biopsy
samples look. Low-grade tumor cells look more like normal cells and are less likely
to grow and spread quickly, while high-grade tumor cells look more abnormal. (All
Ewing tumors are considered high-grade tumors.)
Numbers or letters after T, N, M, and G provide more details about each of these
factors.

**T categories of bone cancer**

T0: There is no evidence of a main (primary) tumor.

T1: The tumor is 8 cm (around 3 inches) across or less.

T2: The tumor is larger than 8 cm across.

T3: The tumor is in more than one site in the same bone.

**N categories of bone cancer**

N0: There is no spread to regional (nearby) lymph nodes.

N1: The cancer has spread to nearby lymph nodes.

**M categories of bone cancer**

M0: There is no spread (metastasis) to distant organs.

M1a: The cancer has spread only to the lungs.

M1b: The cancer has spread to other distant sites in the body.

**Grades of bone cancer**

GX: Grade can't be assessed

G1-G2: Low grade

G3-G4: High grade

(All Ewing tumors are considered G4.)
Stage grouping

Once the T, N, and M categories and the grade of the bone cancer have been determined, the information is combined and expressed as an overall stage. The process of assigning a stage number is called *stage grouping*. The stages are described in Roman numerals from I to IV (1-4), and are sometimes divided further.

Stage IA*

**T1, N0, M0, G1 to G2 (or GX):** The tumor is 8 cm across or less (T1) and is low grade (or the grade can’t be assessed). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).

Stage IB*

**T2 or T3, N0, M0, G1 to G2 (or GX):** The tumor is either larger than 8 cm across (T2) or it is in more than one place in the same bone (T3). It is low grade (or the grade can’t be assessed). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).

Stage IIA

**T1, N0, M0, G3 to G4:** The tumor is 8 cm across or less (T1) and is high grade (G3 or G4). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).

Stage IIB

**T2, N0, M0, G3 to G4:** The tumor is larger than 8 cm across (T2) and is high grade (G3 or G4). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).

Stage III

**T3, N0, M0, G3 to G4:** The tumor is in more than one place in the same bone (T3). It is high grade (G3 or G4). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).

Stage IVA

**Any T, N0, M1a, any G:** The tumor has spread only to the lungs (M1a). It has not spread to the lymph nodes or to other distant sites. (It can be any size or grade.)
Stage IVB (if either of these applies)

Any T, N1, any M, any G: The tumor has spread to lymph nodes (N1). It can be any size or grade, and may or may not have spread to other distant sites.

Any T, any N, M1b, any G: The tumor has spread to distant sites other than the lungs (M1b). It can be any size or grade.

*All Ewing tumors are classified as G4 (high grade), so they are never stage I bone cancers.

Localized vs. metastatic stages

Doctors use a simpler system for staging Ewing tumors to determine how best to treat them. In this system, the cancers are classified as either localized or metastatic.

Localized Ewing tumors

A localized Ewing tumor is thought to be confined to the area where it started and may also have reached nearby tissues such as muscle or tendons. A Ewing tumor is considered localized only after all of the imaging tests (x-rays, CT or MRI scans, and PET or bone scans) and the bone marrow biopsy and aspirate (if done) do not find it has spread to other distant areas.

Even when imaging tests do not show that the cancer has spread to distant areas, many patients are likely to have micrometastases (very small areas of cancer spread that can’t be detected with tests). This is why chemotherapy, which can reach all parts of the body, is an important part of treatment for all Ewing tumors.

Metastatic Ewing tumors

A metastatic Ewing tumor has clearly spread from where it started to distant parts of the body. Most of the time, it spreads to the lungs or to other bones or the bone marrow. Less commonly, it spreads to the liver or lymph nodes.

About 1 in 4 patients will have obvious spread that is found by imaging tests. But as mentioned above, many other patients are likely to have small amounts of cancer spread to other parts of the body that can’t be seen on imaging tests.

- References
Survival Rates for Ewing Tumors by Stage

Survival rates are often used by doctors as a standard way of discussing a person’s prognosis (outlook). Some people may want to know the survival statistics for those in similar situations, while others may not find the numbers helpful, or may even not want to know them. If you do not want to read about survival statistics for Ewing tumors, skip to the next section.

When discussing cancer survival statistics, doctors often use a number called the 5-year survival rate. The 5-year survival rate refers to the percentage of patients who live at least 5 years after their cancer is diagnosed. Of course, many people live much longer than 5 years (and many are cured).

In order to get 5-year survival rates, doctors have to look at people who were treated at least 5 years ago. Improvements in treatment since then might result in a better outlook for patients now being diagnosed with Ewing tumors.

Survival rates are often based on previous outcomes of large numbers of people who had the disease, but they aren’t a prediction of what will happen in any person’s case. The stage of a person’s cancer is important in estimating their outlook. But many other factors can also affect a person’s prognosis, such as their age, the location of the tumor, and how well the cancer responds to treatment.

Localized tumors

With current treatment, the overall 5-year survival rate for patients with Ewing tumors that are still localized when they are first found is around 70%.

Metastatic tumors
When the cancer has already spread when it is diagnosed, the 5-year survival rate is about 15% to 30%. The survival rate is slightly better if the cancer has only spread to the lungs as opposed to having reached other organs.

**Other factors affecting prognosis**

Factors other than the stage of the cancer can also affect survival rates. Factors that have been linked with a better prognosis include:

- Smaller tumor size
- Main tumor is on an arm or leg (as opposed to chest wall or pelvis)
- Normal blood LDH level
- Good tumor response to chemotherapy
- Age younger than 10

Even when taking these other factors into account, survival rates are at best rough estimates. Your child’s doctor is your best source of information on this topic, as he or she is familiar with your situation.

- **References**
- See all references for Ewing Family of Tumors

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**What Should You Ask the Doctor About Ewing Tumors?**

It’s important to have frank, open discussions with your cancer care team. They want to answer all of your questions, no matter how minor they might seem. For instance, consider these questions:

- What kind of Ewing tumor do I (does my child) have?
- Has the cancer spread beyond the main (primary) site?
- What is the stage of the cancer and what does that mean?
• Will we need other tests before we can decide on treatment?
• How much experience do you have treating this type of cancer?
• Will I (we) need to see other doctors?
• What are our treatment options?
• What do you recommend and why?
• How soon do we need to start treatment?
• What should I (we) do to be ready for treatment?
• How long will treatment last? What will it be like? Where will it be done?
• How will treatment affect our daily lives?
• What are the risks and side effects of the suggested treatments?
• Which side effects start shortly after treatment and which ones might develop later on?
• Will treatment affect my child’s ability to grow and develop?
• Will treatment affect my child’s future ability to have children?
• What are the chances of the cancer coming back after treatment? What will we do if this happens?
• What type of follow up and rehab will be needed after treatment?
• Are there nearby support groups or other families who have been through this that we could talk to?

Along with these sample questions, be sure to write down some of your own. For instance, you might want more information about recovery times so that you can plan your work or school schedules. Or you may want to ask about second opinions or about available clinical trials.

Also keep in mind that doctors are not the only ones who can provide you with information. Other health care professionals, such as nurses and social workers, may have the answers to some of your questions. You can find out more about speaking with your health care team in Talking With Your Doctor.

• References
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