**Call the Doctor If**

- Your incision is red, warm and tender to touch, or has anything draining from it.
- You have a temperature over 101ºF (38.5ºC).
- Fluid leaks from your vagina
- You have vaginal bleeding
- You don’t feel the baby move every day
- You have persistent back pain, cramping, abdominal tightening or pelvic pressure.
- You have chest pain or difficulty breathing.

We hope this booklet will help answer your questions and serve as a resource to you and your family throughout your experience with Fetal Surgery.

**Introduction**

Fetal surgery (FS) is an innovative treatment for certain congenital abnormalities that are life threatening for an unborn baby. Surgical treatment during pregnancy may allow improved fetal development and a chance for the baby’s survival after birth. At UCSF Medical Center, several types of fetal defects are being treated with FS, including diaphragmatic hernia, urinary tract obstruction, cystic lung mass, sacrococcygeal teratoma, twin-twin transfusion syndrome and myelomeningocele. Your doctor will explain your fetus’ problem in greater detail and how intrauterine surgery can help. FS is performed either through a large incision to open your uterus or through tiny incisions using special miniature instruments in the closed uterus. The fetal surgeons will describe these methods in detail.

The purpose of this booklet is to provide information about your hospitalization and your care after discharge. The goal is to decrease your fears, to help you ask questions and educate you about what is involved when you undergo fetal surgery.

**Meeting the Team**

Each person in the Fetal Treatment Team will play a separate but integrated role in your care. They will care for you and your unborn baby as well as answer your questions.
The team includes:

**Perinatologists and Pediatric Surgeons**
These physicians, who specialize in maternal and fetal medicine, will speak with you at length about your baby’s condition, the surgical procedure and possible risks, benefits and complications. The perinatologist manages your postoperative care together with members of the fetal therapy team. The pediatric surgeons perform the surgery on you and your unborn baby.

**Fetal Treatment Coordinator**
The fetal treatment coordinator is a nurse who coordinates your care throughout your experience at UCSF. She will facilitate communication between you and your doctors about what will happen while at UCSF. She will coordinate your various appointments: sonography, echocardiology, laboratory testing and appointments with the medical team members. She also can help make lodging arrangements. Feel free to contact the coordinator any time before surgery or after you leave the hospital if you have concerns.

**Social Worker**
A perinatal social worker will meet you and your support person to help identify ways you can best cope with the stress of this situation. She can tour you around the Intensive Care Nursery (ICN) and help prepare you for what to expect after your baby is born. She is available throughout your and your baby’s stay.

**Sonologist**
A specialist in obstetrical sonography will review the sonograms of your pregnancy to assist the Fetal Treatment Center team in diagnosing your unborn baby’s problem. The sonographer provides assistance during surgery and evaluates the procedure by checking on the fetus frequently afterward.

**Anesthesiologist**
This physician administers anesthesia and monitors you and your baby during surgery. He will meet with you prior to surgery to discuss your medical history and previous anesthetic history. After the operation, the anesthesiologist is responsible for your pain management.

**Medications**
You may be on tocolytics until 37 weeks’ gestation. The most commonly used tocolytic is nifedipine. If needed, pain medication will be provided. Begin taking your prenatal vitamins again after discharge.

**Diet**
Since your activity is decreased, you may not feel like eating. We will provide you with a bedrest diet and encourage you to eat six very small meals a day. Drinking six to eight glasses of water a day will help prevent the constipation that can result from bedrest.

**Exercise**
You will receive instructions for bedrest exercises to help you keep some muscle tone. The most important exercise is flexing your foot towards your head and then pointing it. Do the bedrest exercises as often as you can. Also, remember to turn and change sides at least every two hours when you are lying down.

**Managing at Bed rest**
Be sure to have help available, especially if you have children. Make a schedule for yourself. Schedule a change of rooms to spend time in, take naps, make telephone time, plan project time and other diversional activities. Talk to other mothers who have had to stay in bed during pregnancy.

**Follow-up Appointments**
You will see the perinatologist once per week after discharge. You also may have an ultrasound once per week or more often if deemed necessary by your doctor. Your baby and uterus will be monitored weekly in the Perinatal Testing Center.

**Important Telephone Numbers:**
- Fetal Treatment Center (800) RX-FETUS
- 24 Hr Pediatric Surgery (415) 476-2538
- Labor & Delivery (415) 353-1787
- Perinatal Testing Center (415) 353-2722
- Perinatologist - Outpatient Clinic (415) 353-2223
- Intensive Care Nursery (415) 353-1565
Diet

No food or fluids will be allowed by mouth until digestive function returns. You will still get fluids through your IV.

Frequent mouth rinses, tooth brushing and moist swabs are used to relieve dry mouth. Your doctor will advance your diet as tolerated. Once you have been able to pass gas rectally, fluid will be initiated. If you are able to tolerate fluids, you will start solid food.

Discharge Preparation

Generally, you will be able to leave around the fourth to seventh day after surgery if you meet the following goals:

- Premature labor is controlled so that there are less than five contractions in an hour and no cervical change.
- You have walked the halls at least once without increasing uterine activity.
- You have a good understanding of your medications and home care.

Some fetal procedures make it necessary for you to stay in San Francisco until delivery. You will be informed of this prior to undergoing surgery.

Home Care

Activity

You will be on modified bedrest until 37 weeks’ gestation. This usually means you are able to get up for meals, shower, use the bathroom and go from one room to another. Most of the time, you should be lying down on your side. Your doctor will be more specific about any alteration in this plan. Bedrest promotes blood flow to your uterus and baby, and decreases pressure placed on your cervix - factors that help decrease uterine contractions.

Operating Room Nurses

The nurses who assist the surgeons in the operating room often meet you before surgery and can answer questions about the procedure. You will see them briefly when you arrive in the operating room the day of the surgery.

Clinical Nurse Specialist and Obstetric Nurses

The clinical nurse specialist will discuss the hospital experience and home care with you prior to your admission. Medical, social, emotional and financial considerations will be addressed. She will develop a postoperative plan of care for you and oversee staff implementation of this care. Throughout your hospital stay, the obstetric nurses will provide you with expert care. They will help you recover from surgery, obtain pain relief, prevent premature labor and oversee the fetus’ well being.

Prehospital Planning

Support

It is extremely important to have someone close to you stay with you for the entire time you are in San Francisco. After fetal surgery, you will be on bedrest to prevent preterm labor. During that time, you will be unable to care for yourself and will need others to help you. This is a stressful time and you will need someone you can depend on and trust.

Betamethasone

This medication is a steroid that is sometimes given to the mother prior to surgery in two injections 12 to 24 hours apart to accelerate your baby’s lung development. It may be given again as you get closer to delivery. It has benefits on the baby, but will increase the sugar in your blood stream and can make you a little more susceptible to infections.

Blood Transfusions

Although you will be undergoing major surgery, it is unlikely that you will need a blood transfusion. California law requires physicians to inform patients undergoing surgery that they have a risk, small as it may be, of needing a blood transfusion. The patient is
then entitled to obtain either designated donor blood from a source chosen by the patient or blood from a blood bank. Your doctor will further discuss this with you, but you must make arrangements for designated donor blood several days in advance of your surgery.

You may need fibrin glue, which is made from a clotting substance in blood. This substance strengthens the closure of your uterus after the fetal surgery. Your partner can’t donate blood for a transfusion but he may donate blood to make fibrin glue at the UCSF Blood Donor Center three to four days before the procedure.

**Hospital Admission**

Plan to arrive at UCSF Medical Center the evening before surgery for admission to the Perinatal Service on Floor 15. An obstetrical nurse will obtain a nursing history, perform a physical examination and assess your baby’s heart rate using an electronic fetal monitor. You also will wear a uterine monitor for a brief period before surgery to detect uterine contractions and to determine the baby’s usual heart rate pattern.

**Care Before Surgery**

Routine preoperative care will include:

- Taking urine and blood samples
- Typing and cross matching blood type in case of a rare transfusion
- Intravenous infusion to provide water and electrolytes
- Nothing to eat after midnight
- Signing surgical consent
- Shaving of abdomen
- Wearing thick elastic stockings called TEDS
- Taking Alkagold to decrease stomach acids

in place for about 48 to 72 hours. Bedpans must be used for bowel movements until your catheter is removed. As your condition improves and uterine activity is controlled, you will be allowed to go to the bathroom and to shower. Depending on your condition, you will be able to get up to go to the bathroom by approximately the third postoperative day. By the fifth postoperative day, you may walk to the nurse’s station or down the hall once or twice a day. Again, this depends on your condition. Your perinatologist will determine your activity level during your recovery period.

**Treatments**

You will be expected to do a few things after surgery to prevent or treat lung and circulation complications from surgery and bedrest.

- Using an incentive spirometer, a small, simple piece of equipment, helps you breathe in deeply and open your lungs as much as possible. This exercise should be repeated five times each hour you are awake. Your nurse will show you how to use this device.

- Deep breathing exercises will help you keep all airways clear.
  - Breathe in slowly allowing your abdomen to rise and lungs to fill with air.
  - Hold the air for about five seconds.
  - Exhale slowly through your nose and mouth.

- Turn at least every two hours from side to side. You will be assisted as needed until you are able to accomplish this on your own.

- Movement and turning:
  - Increase circulation
  - Promote deep breathing
  - Relieve pressure areas on skin
  - Foot flexion exercises improve circulation and help prevent blood clots. Your nurse will instruct you on how to perform them.
Some of these side effects subside as your body becomes used to terbutaline. Stool softeners may be prescribed as needed. You should notify your physician of a persistent headache. You will need to be tested for gestational diabetes to help us to know how well you will tolerate this drug.

**Pain Management**

A continuous infusion of morphine is the most commonly used method of pain management. This infusion is done through an epidural catheter that stays in your back for a few days. Often a numbing medicine called marcaine is added for improved pain relief. After the epidural catheter is removed, you will receive oral pain medications. Possible side effects of morphine include:

- Itching
- Grogginess
- Slow breathing
- Nausea and vomiting

These medications will cross through the placenta and a very small amount will go to your baby. This will not harm your baby and may in fact help your baby be comfortable.

**Antibiotics**

Since infection is a possibility with any surgery, you will be given antibiotics in your IV for at least 48 hours and you will be observed for signs and symptoms of infection. Please let your doctor know if you are allergic to any antibiotics.

**Activity**

You will be expected to remain in bed resting on your side. This position is best for blood flow to your baby and your uterus and helps decrease uterine contractions. The urinary catheter will remain

**During Surgery**

The operating room nurse will escort you to the operating room. Many of the health care providers previously mentioned will be present to assist in the management of your care. During open fetal surgery, the anesthesiologist will monitor your heart and control your breathing through a tube in your throat and airway. He also may monitor your baby’s heart rate. The OR and scrub nurses manage and coordinate all aspects of the operative procedure. The perinatologist will assist in monitoring you and your baby during the procedure and will recommend tocolytic medicines to prevent contractions and preterm labor.

**Immediately After Surgery**

After surgery you will be cared for on the obstetrical ward (Floor 15 Perinatal Service). When you awaken from anesthesia, you will notice a variety of tubes and medical devices used to monitor or treat you and your baby. They will include:

- A narrow flexible tube called an I.V. in your vein *(to give you fluids and medicines)*
- An oxygen mask to provide extra oxygen after surgery when people don’t breathe as deeply
- Fetal heart rate monitor to check on the baby and show any uterine contractions
- Foley catheter to collect urine from the bladder so it is not necessary to use the bathroom
- Epidural catheter in your back to deliver continuous pain medication
- A sequential compressive device (SCD) to help maintain circulation in your legs

A transparent dressing will cover your abdominal incision so that your baby can be monitored more easily and the site can be observed without removing the dressing.
The Postoperative Recovery Period

This period usually lasts four to seven days. You will receive care in a room in the Labor and Delivery unit. The electronic fetal/uterine monitor will be used to assess your baby’s heart rate and contractions. Preterm labor is the most common complication of fetal surgery.

Signs of preterm labor include:

- Abdominal tightening
- Cramping
- Backache
- Pelvic pressure
- Change in vaginal discharge
- Leakage of vaginal fluid
- Bleeding

Medications for Preterm Labor (Tocolytics)

You may receive one or more of the following tocolytics to prevent uterine contractions and preterm labor.

**Indocin Suppositories**

Indocin helps stop production of prostaglandins, substances released from your uterus and cervix that cause uterine activity. It is given by rectal suppository or by mouth before and for up to 48 hours after surgery. The most common side effects are maternal stomach upset and a decrease in fetal amniotic fluid. These side effects will be monitored daily. An uncommon side effect includes narrowing of a blood vessel in the fetal heart called the ductus. This is monitored by fetal echocardiography.

**Magnesium Sulfate (MgSO4)**

MgSO4 relaxes smooth muscle. Since your uterus is a muscle, MgSO4 decreases the frequency and strength of contractions. Your health care team will monitor you closely to determine your response to MgSO4. Since it is excreted in your urine, an accurate record of your fluid intake and urinary output will be kept. Daily weights will be obtained and blood levels will be drawn to insure that side effects are limited and not severe. The side effects of intravenous MgSO4 include:

- Flushing
- Sweating
- Muscle weakness (wet dishrag feeling)
- Nausea and vomiting
- Feeling sleepy and tired
- Blurred vision
- Fluid in the lungs (pulmonary edema)

After one or two days, you will be weaned from the MgSO4 to another tocolytic taken orally in pill form to control uterine activity.

**Nifedipine**

Nifedipine relaxes your uterus. It can be given in pill form every four to six hours and usually is started while decreasing your Indocin dose. Side effects of nifedipine include:

- Low blood pressure
- Flushing
- Rash
- Headache

**Terbutaline**

Terbutaline relaxes your uterus. It can be delivered at very low but effective doses in a pill form.

The side effects of terbutaline include:

- Heart rate is faster than normal, usually 90 to 110 beats per minute
- Increased sugar in the bloodstream
- Shaky feeling
- Nausea
- Constipation
- Feeling of warmth
- Headache