



Appendix 29-A Thoracoabdominal Resection of Neuroblastoma

Neuroblastoma is a cancer of the sympathetic nervous system. There are approximately 650 new cases each year in the United States. About three-fourths of cases occur in children under the age of four and almost all in children ten years old or younger. There is no known cause of neuroblastoma. Most children diagnosed with neuroblastoma receive chemotherapy. After about four courses of chemotherapy, it is time to have surgery to remove the tumor.

A thoracoabdominal resection means the surgeon will make a large incision starting in the chest (thoraco) area and going down to the abdomen (abdominal). The reason the surgeon makes a big incision is to have a good look at all areas where the cancer might be and to see all the blood vessels to do the surgery safely.

You and your child will come to the surgical clinic sometime in the week before surgery to meet with the surgeon and other members of the surgical team (such as nurses and an anesthesiologist) to ask and have questions answered. Your child will have some blood taken at this visit and may have other tests done if they are needed. All of the paperwork for surgery will be done at this visit so your child does not have to stay in the hospital the night before the surgery. If there are medications your child will need to take before surgery, or any s/he is on that need to be stopped, you will be told.

The anesthesiologist or nurse will give you specific guidelines as to what your child may eat, or NOT EAT, in the hours before surgery. You must follow these guidelines or the surgery may be cancelled.

You will bring your child to the pre-surgical area the morning of surgery. You may bring clothes for your child for after the surgery and any special items you think the child will want. Do not bring any valuables. You will be given a specific time to arrive at the hospital and should arrive *no later* than that time. After you arrive, the following will happen:

1. A nurse will ask you some questions and make sure the child has followed the diet guidelines. S/he will take your child's temperature, blood pressure and heart rate.
2. A name band will be placed on the child's wrist and you will be asked to change your child into a hospital gown. Any jewelry should be removed.
3. An intravenous will be started in most cases and any preoperative medicines will be given.
4. You will wait with your child for someone from the operating room to come and escort you there.

5. You will be told where to wait while your child is in the operating room. Once the surgery is finished, you will be directed to the recovery room to be with your child. The surgeon will find you to tell you how the operation went.

This is a big surgery and your child will be in the hospital for 7-10 days afterward. Before the surgery, the anesthesiologist will place a breathing tube to help during the surgery. This tube may still be in place when you see your child in the recovery room. Your child will also have other tubes put in ONCE S/HE IS ALREADY ASLEEP. These will include:

1. A tube into the bladder (foley catheter) to drain the urine.
2. A large intravenous (IV) line for medicine and fluids (unless s/he already has one)
3. A catheter (tube) into an artery in the wrist to monitor the heart during surgery (this is usually removed before the child goes into recovery).
4. A tube from the nose into the stomach (a nasogastric or NG tube) to keep the stomach empty during and for the first few days after surgery.
5. A tube into the chest to drain any fluid or air after the surgery (called a chest tube). During the surgery the surgeon will safely deflate the lung on the side of the incision to let him see inside the chest. The lung will be reinflated at the end of surgery. The tube goes in between the lung and the chest wall and helps make sure the lung fills up properly.
6. An epidural catheter (a small tube put into the back) to give pain medicine.

After the surgery your child will either go to a pediatric intensive care unit or a step down intensive care unit to recover. You will be allowed to stay with your child. The doctors and nurses will monitor your child's condition. The bladder catheter will stay in about 2 days, the large IV until discharge (or until therapy is complete), the stomach (NG) tube until the bowels recover (about 2-3 days), the chest tube until the lung is better (about 2-3 days), and the epidural for about 2-3 days.

Your child will have chest X-rays done at least daily to monitor the lung. We will show your child how to use a special breathing toy to help the lung get better and help prevent pneumonia. S/he will not be able to eat until the bowel starts to work. When s/he can eat, we will give her water and then other fluids and slowly bring back food. The nurses will get your child up and out of bed as soon as possible to help the lung and the bowel get better more quickly. We will give her/him pain medicine and ask you to help us make sure s/he is comfortable. After about 3 days, the pain medicine will be given by mouth.

There will be a bandage over the incision and over the place where the chest tube comes out. These will be changed by the surgical team the first time and then by the nurses. Usually the stitches are the dissolving kind, but there is one stitch at the chest tube site. This will be removed by the surgical team about a week after the chest tube is removed. Your child will be able to shower about 3 days after surgery, but the incision cannot be under water (no bath) for 2 weeks. It takes 6-8 weeks for the incision to heal completely.

Before going home, we will make sure your child is eating and drinking, having bowel movements, has well controlled or no more pain and that the incision is healing well. Any medications your child will need will be reviewed and you will be given prescriptions for them.

You will be given the surgeon's phone number and emergency phone numbers. You will also be given an appointment to come back to the surgical clinic. Your child may return to school, but may not participate in gym class for 2 months. We will give you a note for that.

You should call the doctor if your child develops fever, increased pain, belly swelling or any other symptoms that seem worrisome.

Please reproduce and distribute this sheet to your surgery families. This material can also be downloaded at www.APSNA.org.

Copyright 2006, Laura San Miguel. Copied with permission by Jones and Bartlett Publishers, Sudbury, MA."

Appendix 29-B Resection of an Extremity Rhabdomyosarcoma

Rhabdomyosarcoma is the most common soft tissue sarcoma in childhood. The cause is unknown and it can occur in many different body sites. The extremities (arms and legs) account for about 18% of cases. If your child has been diagnosed with rhabdomyosarcoma in one of his/her extremities, surgery may be recommended to remove the tumor.

You and your child will come to the surgical clinic sometime in the week before surgery to meet with the surgeon and other members of the surgical team (such as nurses and an anesthesiologist) to ask and have questions answered. Your child will have some blood taken at this visit and may have other tests done if they are needed. All of the paperwork for surgery will be done at this visit so your child does not have to stay in the hospital the night before the surgery. If there are medications your child will need to take before surgery, or any s/he is on that need to be stopped, you will be told.

The anesthesiologist or nurse will give you specific guidelines as to what your child may eat, or NOT EAT, in the hours before surgery. You must follow these guidelines or the surgery may be cancelled.

You will bring your child to the pre-surgical area the morning of surgery. You may bring clothes for your child for after the surgery and any special items you think the child will want. Do not bring any valuables. You will be given a specific time to arrive at the hospital and should arrive *no later* than that time. After you arrive, the following will happen:

1. A nurse will ask you some questions and make sure the child has followed the diet guidelines. S/he will take your child's temperature, blood pressure and heart rate.
2. A name band will be placed on the child's wrist and you will be asked to change your child into a hospital gown. Any jewelry should be removed.
3. An intravenous (IV) will be started in most cases and any preoperative medicines will be given.
4. You will wait with your child for someone from the operating room to come and escort you there.
5. You will be told where to wait while your child is in the operating room. Once the surgery is finished, you will be directed to the recovery room to be with your child. The surgeon will find you to tell you how the operation went.

Your child will be in the hospital for 3-7 days after the surgery. S/he will recover in a pediatric step down unit or a regular pediatric unit. The doctors and nurses will monitor your child's pain, heart rate and blood pressure, check the dressing over the incision and the fingers or toes of that extremity. The dressing will be removed after 2 days and the incision will be checked by the surgical team. A new dressing may be put on or the incision may be left open. There will either be dissolving stitches, regular stitches or staples holding the incision together. If there are stitches or staples that need to be removed, the surgical service will do this about 7-10 days after the surgery. Your child may have a drain in place to remove any fluid that might be in the area of the surgery. This is called a Jackson Pratt (JP) drain. This will be removed by the surgical service when the drainage decreases, usually after 3-5 days.

Your child will be given pain medicine through the IV for the first few days after surgery and then we will switch medicine by mouth. S/he will be able to drink the night of the surgery and eat food if s/he is feeling well enough. The arm or leg will be elevated and immobilized for a few days. The doctor will tell the nurses when to start range of motion exercises. The incision needs to stay dry for 2-3 days. After that s/he will be able to shower. We do not want the incision under water for 2 weeks. If there are stitches or staples holding the wound together, ask the surgeon when your child may get the area wet.

Before going home, we will make sure your child is eating and drinking, having bowel movements, has well controlled or no more pain and that the incision is healing well. We will give you any instructions about caring for the wound at home. Any medications your child will need will be reviewed and you will be given prescriptions for them. If there are exercises for you to do with your child at home, or s/he will need some rehabilitation, we will give you those instructions. You will be given the surgeon's phone number and emergency phone numbers. You will also be given an appointment to come back to the surgical clinic. Your child may return to school, but may not participate in gym class for 2 months. We will give you a note for that. It takes 6-8 weeks for the incision to heal fully.

You should call the surgeon's office if your child develops fever, swelling or significant new pain in the area of the surgery, redness or drainage from the incision or any other symptom that seem worrisome.

Please reproduce and distribute this sheet to your surgery families. This material can also be downloaded at www.APSNA.org.

Copyright 2006, Laura San Miguel. Copied with permission by Jones and Bartlett Publishers, Sudbury, MA."

Appendix 29-C Laparotomy for removal of an abdominal or pelvic tumor

If your child has an abdominal or pelvic tumor, s/he may have surgery to remove it. A laparotomy is an incision (or cut) into the abdomen, through which the surgeon can see what is happening and remove tumors.

You and your child will come to the surgical clinic sometime in the week before surgery to meet with the surgeon and other members of the surgical team (such as nurses and an anesthesiologist) to ask and have questions answered. Your child will have some blood taken at this visit and may have other tests done if they are needed. All of the paperwork for surgery will be done at this visit so your child does not have to stay in the hospital the night before the surgery. In many cases, the bowel will need to be cleaned out the day before surgery. This is called a bowel prep. We will give you some antibiotics and some medicine for your child to drink the day before surgery. We will give you specific instructions about when to give the medicine and how much of each one. We will also give you our phone number to call if you have questions or concerns.

During the preoperative visit, the anesthesiologist or nurse will give you specific guidelines as to what your child may eat, or NOT EAT, in the hours before surgery. You must follow these guidelines or the surgery may be cancelled.

You will bring your child to the pre-surgical area the morning of surgery. You may bring clothes for your child for after the surgery and any special items you think the child will want. Do not bring any valuables. You will be given a specific time to arrive at the hospital and should arrive *no later* than that time. After you arrive, the following will happen:

1. A nurse will ask you some questions and make sure the child has followed the diet guidelines. S/he will take your child's temperature, blood pressure and heart rate.
2. A name band will be placed on the child's wrist and you will be asked to change your child into a hospital gown. Any jewelry should be removed.
3. An intravenous (IV) will be started in most cases and any preoperative medicines will be given.
4. You will wait with your child for someone from the operating room to come and escort you there.
5. You will be told where to wait while your child is in the operating room. Once the surgery is finished, you will be directed to the recovery room to be with your child. The surgeon will find you to tell you how the operation went.

This is a big surgery and your child will be in the hospital for 7-10 days afterward. Before the surgery, the anesthesiologist will place a breathing tube to help during the surgery. This tube may still be in place when you see your child in the recovery room. Your child will also have other tubes put in **ONCE S/HE IS ALREADY ASLEEP**. These will include:

1. A tube into the bladder (Foley catheter) to drain the urine.
2. A large IV line for medicine and fluids (unless s/he already has one)
3. A catheter (tube) into an artery in the wrist to monitor the heart during surgery (this is usually removed before the child goes into recovery).
4. A tube from the nose into the stomach (a nasogastric or NG tube) to keep the stomach empty during and for the first few days after surgery.
5. An epidural catheter (a small tube put into the back) to give pain medicine.

After the surgery your child will either go to a pediatric intensive care unit or a step down intensive care unit to recover. You will be allowed to stay with your child. The doctors and nurses will monitor your child's condition. The bladder catheter will stay in about 2 days, the

large IV until discharge (or until therapy is complete), the stomach tube until the bowels recover (about 2-3 days), and the epidural for about 2-3 days.

Even though the surgery did not involve the lungs, the combination of anesthesia and not moving around puts your child at risk for pneumonia. We will show your child how to use a special breathing toy to help the lungs recover from the anesthesia and help prevent pneumonia. S/he will not be able to eat until the bowel starts to work. Once the bowels start to work, we will take out the NG tube. This may take 3-5 days. When s/he can eat, we will give her water and then other fluids and slowly bring back food. The nurses will get your child up and out of bed as soon as possible to help the lung and the bowel get better more quickly. We will give her/him pain medicine and ask you to help us make sure s/he is comfortable. After about 3 days, the pain medicine will be given by mouth.

There will be a bandage over the incision. The surgeon will remove this after about 2 days. There will either be dissolving stitches or regular stitches or staples holding the incision together. If there are stitches or staples to be removed, this is done about 7-10 days after surgery. The nurses and doctors will watch the incision for redness or drainage and swelling. Your child will be able to bathe about 3 days after surgery, but we do not want the incision under water for at least 2 weeks. If there are stitches or staples, ask the surgeon about when your child may bathe.

Before going home, we will make sure your child is eating and drinking, having regular bowel movements, has well controlled or no more pain and that the incision is healing well. Any medications your child will need will be reviewed and you will be given prescriptions for them. You will be given the surgeon's phone number and emergency phone numbers. You will also be given an appointment to come back to the surgical clinic. Your child may return to school, but may not participate in gym class for 2 months. We will give you a note for that. It takes 6-8 weeks for the incision to heal fully.

You should call the doctor if your child develops fever, increased pain, belly swelling or any other symptoms that seem worrisome.

Please reproduce and distribute this sheet to your surgery families. This material can also be downloaded at www.APSNA.org.

Copyright 2006, Laura San Miguel. Copied with permission by Jones and Bartlett Publishers, Sudbury, MA."