Supplementary Online Content


eAppendix.

This supplementary material has been provided by the authors to give readers additional information about their work.
Pre-Class Laryngectomy Survey

Based on your current knowledge about your upcoming total laryngectomy, please answer the following questions by circling the answer that you think is correct.

1. Total laryngectomy means the surgeon will remove my voice box.
   - True  
   - False  
   - I do not know

2. After the surgery, I will be able to breathe through my mouth.
   - True  
   - False  
   - I do not know

3. After the surgery, I will be in the hospital for only 3 days.
   - True  
   - False  
   - I do not know

4. I might need to wear a tube (laryngectomy or tracheostomy tube) to keep my laryngectomy stoma (hole in my neck) open.
   - True  
   - False  
   - I do not know

5. The person taking care of my laryngectomy stoma (my caregiver or me), does not need to wash his or her hands prior to cleaning the stoma or the tube that is in the stoma.
   - True  
   - False  
   - I do not know

6. I should not use any water when cleaning my laryngectomy or tracheostomy tube.
   - True  
   - False  
   - I do not know

7. The person taking care of my stoma (my caregiver or me), needs to clean my laryngectomy stoma and tube at least two times a day.
   - True  
   - False  
   - I do not know

8. If I cannot put the tube back in my neck after I take the tube out to clean it, I should call my doctor’s office.
   - True  
   - False  
   - I do not know

9. If my stoma gets plugged with mucus, I will still be able to breathe just fine.
10. If I am feeling short of breath, I should remove the tube in my neck (or ask my caregiver to remove it), and suction my stoma to make sure it is not clogged with mucus.

True False I do not know

11. If my stoma gets red and warm or I start to notice foul smelling drainage, I should call my doctor.

True False I do not know

12. If I need surgery in the future, then the anesthesiologist can insert the breathing tube through my mouth and then into my lungs.

True False I do not know

13. My perceived readiness and confidence in relation to self-care of my laryngectomy (on a scale of 1-10 with 1 being not ready/confident and 10 being very ready/confident) is:

1 2 3 4 5 6 7 8 9 10

14. My caregiver’s perceived readiness and confidence in relation to self-care of my laryngectomy (on a scale of 1-10 with 1 being not ready/confident and 10 being very ready/confident) is:

1 2 3 4 5 6 7 8 9 10
Day of Hospital Discharge Laryngectomy Survey
Based on the information you learned prior to your surgery about your total laryngectomy, please answer the following questions by circling the answer that you think is correct.

1. Total laryngectomy means the surgeon will remove my voice box.
   
   True  False  I do not know

2. After the surgery, I will be able to breathe through my mouth.
   
   True  False  I do not know

3. After the surgery, I will be in the hospital for only 3 days.
   
   True  False  I do not know

4. I might need to wear a tube (laryngectomy or tracheostomy tube) to keep my laryngectomy stoma (hole in my neck) open
   
   True  False  I do not know

5. The person taking care of my laryngectomy stoma (my caregiver or me), does not need to wash his or her hands prior to cleaning the stoma or the tube that is in the stoma.
   
   True  False  I do not know

6. I should not use any water when cleaning my laryngectomy or tracheostomy tube.
   
   True  False  I do not know

7. The person taking care of my stoma (my caregiver or me), needs to clean my laryngectomy stoma and tube at least two times a day.
   
   True  False  I do not know

8. If I cannot put the tube back in my neck after I take the tube out to clean it, I should call my doctor’s office.
   
   True  False  I do not know

9. If my stoma gets plugged with mucus, I will still be able to breathe just fine.
10. If I am feeling short of breath, I should remove the tube in my neck (or ask my caregiver to remove it), and suction my stoma to make sure it is not clogged with mucus.

True  False  I do not know

11. If my stoma gets red and warm or I start to notice foul smelling drainage, I should call my doctor.

True  False  I do not know

12. If I need surgery in the future, then the anesthesiologist can insert the breathing tube through my mouth and then into my lungs.

True  False  I do not know

13. My perceived readiness and confidence in relation to self-care of my laryngectomy (on a scale of 1-10 with 1 being not ready/confident and 10 being very ready/confident) is:

1  2  3  4  5  6  7  8  9  10

14. My caregiver’s perceived readiness and confidence in relation to self-care of my laryngectomy (on a scale of 1-10 with 1 being not ready/confident and 10 being very ready/confident) is:

1  2  3  4  5  6  7  8  9  10
Day of Hospital Discharge Laryngectomy Patient Practicum

Prior to discharge, the patient must demonstrate proficiency in the following as judged by his or her nurse:

1. Suctioning of the tracheotomy/laryngectomy tube (including hand hygiene and set up of the suction machine).
   - Yes
   - No

2. Cleaning of the laryngectomy stoma (including hand hygiene).
   - Yes
   - No

   - Yes
   - No

4. Administration of tube feeding (if applicable).
   - Yes
   - No
### Day of Hospital Discharge Laryngectomy Coach Practicum

Prior to discharge, the laryngectomy coach/caregiver must demonstrate proficiency in the following as judged by his or her nurse:

1. Suctioning of the tracheotomy/laryngectomy tube (including hand hygiene and set up of the suction machine).
   - [ ] Yes
   - [ ] No

2. Cleaning of the laryngectomy stoma (including hand hygiene).
   - [ ] Yes
   - [ ] No

   - [ ] Yes
   - [ ] No

4. Administration of tube feeding (if applicable).
   - [ ] Yes
   - [ ] No
Barnes-Jewish Hospital and Washington University Physicians are your partners in your journey as you plan for and recover from your total laryngectomy. With this guide, you will start to prepare for your new life without your voice box. During your stay with us we will safely help you recover. By reading this, you’re already on a journey to a rapid recovery.

This is your guide to your new life as a laryngectomee. You will have a team to lead you along the way.

- Use this guide to learn more about what will happen before, during and after surgery.
- Complete the guide checklists.
- Bring your guide along with you to all appointments, classes, meetings and your stay at Barnes-Jewish Hospital.
- Review your rapid recovery dates on the next page.
# Rapid Recovery Dates

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Time</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting healthy for surgery</td>
<td></td>
<td></td>
<td>Learn more on page 1</td>
</tr>
<tr>
<td>Getting ready for surgery</td>
<td></td>
<td></td>
<td>Learn more on page 2</td>
</tr>
<tr>
<td>Surgery evaluation at the Center for Preoperative Assessment and Planning (CPAP)</td>
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<tr>
<td>Total Laryngectomy class</td>
<td></td>
<td></td>
<td>Learn more on page 4</td>
</tr>
<tr>
<td>Let's learn about the surgery experience</td>
<td></td>
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<tr>
<td>Preoperative Education with the Speech Language Pathologist</td>
<td></td>
<td></td>
<td>Learn more on page 5</td>
</tr>
<tr>
<td>Learn about your rehabilitation 1-2 weeks before your surgery</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day of surgery</td>
<td></td>
<td></td>
<td>Learn more on page 6</td>
</tr>
<tr>
<td>1-3 days before surgery, your surgeon's office will call you and tell you what time to arrive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning your discharge</td>
<td></td>
<td></td>
<td>Learn more on page 12</td>
</tr>
<tr>
<td>Meeting with your care team</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Your journey home</td>
<td></td>
<td></td>
<td>Learn more on page 14</td>
</tr>
<tr>
<td>Visit from your home care team</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up appointment</td>
<td></td>
<td></td>
<td>Learn more on page 17</td>
</tr>
<tr>
<td>Talk about your progress with your surgeon and next steps of your treatment plan</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continuing rapid recovery</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Visit an outpatient therapy center</td>
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<td></td>
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</tbody>
</table>

**If you have questions at any point in your journey,**

**contact:** ___________________________ **Phone number:** ___________________________

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GETTING HEALTHY FOR SURGERY

The plan is to take steps to feel good about your health – starting now. Here is a checklist that will guide you to be your healthiest for your new start

☐ Check in with your primary care doctors

It is important to check in with your primary care physician to make sure that he/she is updated about your health status.

☐ Choose a coach for your journey

• A designated “coach” can help you stay safe, learn your new wound care and be your best during this journey. Select a family member or friend who can be by your side to help you stay on track to complete your checklists and be successful.

• Your coach will help you meet your surgery planning and recovery goals.

• Your coach will help you become independent faster.

• When you first arrive home, your coach can stay with you for a few days or visit daily. This home support will encourage you in your recovery.

☐ Healthy teeth

Schedule an appointment with your dentist before surgery to make sure your teeth are in their best health. If you will be having radiation therapy, you may need unhealthy teeth removed prior to starting.

☐ Stop smoking – it will help prevent your cancer from coming back

Stopping smoking is important to prevent your cancer from coming back. Please try our freedom from smoking program. This free program will help you change habits, reduce stress and teach you how to prevent relapses. For more information call 314-362-7844 or visit us at www.siteman.wustl.edu/quitsmoking.aspx. If this program will not work for you, please call your local hospital or one of the programs offered by the state of Missouri/Illinois by calling 1-800-QUIT-NOW (1-800-784-8669)

☐ Diabetes

It is very important to control your blood glucose levels during your journey. When you control your blood glucose, you will heal faster, minimize wound complications and assist in preventing infection.

☐ Nutrition

Swallowing may be difficult, but maintaining nutrition is important to help you heal your surgical wounds. You may require supplemental nutrition by mouth or via a tube in your stomach.
GETTING READY FOR SURGERY

The surgical evaluation is an important step to your recovery.

Visit our Center for Preoperative Assessment and Planning (CPAP)

- Before your surgery, you will visit our CPAP. Staff from CPAP are from anesthesiology and they will evaluate you for surgery and guide you on how to be your healthiest for surgery. Be sure to bring this guide with you to your CPAP appointment.
- CPAP is located at the Center for Advanced Medicine, on the corner of Forest Park and Euclid avenues.
  - Valet parking is available at the front entrance, located on Parkview Place just off Euclid Avenue.
  - Self-parking is available in the North Garage, located just across Euclid Avenue to the east.
    The parking garage connects via a third-floor walkway.
- If you need to change or reschedule your surgical evaluation date, please call 314-454-8134.

What to expect during your surgical evaluation

Health Review

- We will ask you about your medical history and perform a health exam. We may ask you to get a blood test, X-rays or an EKG during your evaluation.
- We will talk about your health conditions and past surgeries. If you have a list of health conditions, medications, allergies and surgeries, please bring it with you.

Medications

- During your health exam, your care team will ask about the over-the-counter medications, prescriptions, vitamins and herbal supplements you take. If you have prescribed medication, it is important to keep taking the medication to keep you healthy. Your care team will give you instructions if you need to stop taking any medications.
- Fill in a medication sheet on page 3 to be ready to discuss your health and medication needs with us. If you have a prescription card, please bring this with you.
- Bring your insurance card and advance directive, if you have either.

YOUR MEDICATIONS

Please list your over-the-counter medications, prescriptions, vitamins and herbal supplements you take on this planning sheet. This will help you prepare for your surgical evaluation at our Center for Preoperative Assessment and Planning.

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>DOSE (STRENGTH)</th>
<th>HOW MANY TIMES A DAY</th>
<th>WHY DO YOU TAKE THIS MEDICATION?</th>
<th>PRESCRIBING PHYSICIAN</th>
</tr>
</thead>
</table>

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1-2 WEEKS BEFORE SURGERY

Barnes-Jewish team members take pride in providing an excellent learning experience during your pre-op class. If you have questions, call your surgeon’s office. Phone numbers are listed on page 20.

What to expect during your class
• Opportunity to ask questions.
• Learn about your post-laryngectomy care while in the hospital and after discharge.
• Understand the changes to your body that occur after your laryngectomy.
• Talk about ways to stay at your best health.
• Gain ideas on how to be independent and find out what equipment can help you at home. To review what equipment is going to be discussed, go to page 19.

PLEASE BRING THIS GUIDE TO YOUR CLASS AND ON EVERY STEP OF YOUR RECOVERY JOURNEY.

Your laryngectomy coach should accompany to your pre-op class and appointments.

1-2 WEEKS BEFORE SURGERY

Do you think you may have an infection?
• Call your surgeon’s office if you feel sick or you think you may have an infection of any kind, such as respiratory, bladder, skin or tooth infection.

Do you have any open wounds?
• Check your skin for open sores, wounds and rashes. If you have any questions call your surgeon’s office.

Complete the “set up your home” checklist on page 7.

The speech pathologists are an important part of your cancer team. Meeting with a speech pathologist is important to help learn how to take care of your laryngectomy stoma. They are located in the Center for Advanced Medicine, 11th floor, in the Otolaryngology-Head and Neck Surgery offices. Your surgeon will set up an appointment with them for you.

What to expect during your visit with the speech pathologist
• Opportunity to ask questions about how things will change after your laryngectomy
• Discussions about ways to rehabilitate your voice after surgery
  – Electrolarynx
  – Tracheo-esophageal puncture (TEP)
• Instructions for caring for your laryngectomy stoma
• Discussion of different kinds of accessories for your stoma
  – Tubes (laryngectomy or tracheostomy)
  – Humidification devices
  – Stomal covers (for showering, going outside)
• Discussion about swallowing postoperatively

SPECIAL ALERT: It may be time for you to stop taking certain medications before surgery. Review your CPAP medication instructions.

2-3 DAYS BEFORE SURGERY

Please follow any special instructions you received from your care team or during your CPAP visit.

If you did not already, please complete the “set up your home” checklist on page 7.
• For a successful rapid recovery, your home will need to be in order and ready for you to return.

Pack your bags. Complete the “what to bring” checklist on page 8.
NIGHT BEFORE SURGERY

Please follow and check off each box when complete. Completing this checklist to the best of your ability is your contribution to ensuring a safe and successful surgery.

☐ You cannot eat or drink anything after midnight, including chewing gum, lozenges, coffee, tea or water, unless you receive specific instructions from your surgeon.

☐ Pack your bags. Please complete the “what to bring” checklist on page 8.

DAY OF SURGERY

Please follow and check off each box when complete. Completing this checklist to the best of your ability is your contribution to ensuring a safe and successful surgery.

BEFORE YOU ARRIVE:

☐ Do not use any nail polish, lotions, deodorant, makeup, perfume or body sprays on the day of surgery. Come “natural.”

☐ Take medications that you were instructed to take by the CPAP clinic on the morning of your surgery, with a sip of water.

☐ Follow any special instructions given to you for the morning of surgery. For example, your surgeon might request that you not have blood drawn or an IV placed in a specific arm in the morning of your operation.

SET UP YOUR HOME CHECKLIST

You will need time to recuperate after surgery. You may have some limitations on your physical activities. This checklist will help you prepare your home so your recovery is easier.

☐ For your safety, put your favorite things in places you can easily reach.

☐ Delay mail or have someone take care of your mail.

☐ Have someone take care of your children and pets.

☐ Secure someone to do your yard work.

☐ Do laundry.

☐ Clean your home.

☐ Make sure all stairs at your home have a sturdy railing.

☐ Plan to be independent after your surgery by borrowing or purchasing items to help you while home. To review equipment, go to page 19.
WHAT TO BRING TO THE HOSPITAL

- An attitude of success - you will soon be on a journey to recovery.
- This guide booklet
- Phone numbers of anyone you may want to talk with during your stay at Barnes-Jewish Hospital
- Your completed health history
- Your medication record
- Your insurance card
- A photo ID, such as a driver’s license
- Your prescription card

PLEASE LEAVE THE FOLLOWING ITEMS AT HOME

- Jewelry
- Valuables such as credit cards, checks and large amounts of money
- Medications - your care team will give you all necessary medications while you are at Barnes-Jewish Hospital

DAY OF SURGERY

Check-in

- Check in at the surgery waiting area on the main floor of Barnes-Jewish Hospital south campus. If you need directions, please visit the information desk located on the main level.
- After you check in, you will go through hospital registration. Upon completion, your care team member will take you to the pre-surgery holding area.
- The surgical receptionist will give your family member or laryngectomy coach a beeper to allow us to update them about your surgery.

Before going into surgery

- We will review your medications and health history with you.
- We will start an IV in your arm. If you were instructed by your surgeon to keep one of your arms free of IVs, please remind the nurse.
- Your anesthesiologist will talk about the most appropriate anesthetic for you and the plan to best manage your pain after surgery.
- Your surgeon will meet with you to review the surgical plan and mark where the surgery will occur.
- You will meet the nursing staff who will be caring for you in the operating room.
- Before going to the operating room, you will be given medication for comfort.

During your surgery

- Throughout your surgery your surgical team will monitor your breathing, heart rate and blood pressure.
- A catheter, used to drain urine from your bladder, may be placed during your surgery.
- Updates about your progress will be given to the person who holds the beeper in the surgical waiting room.

Right after surgery

- Usually, you will wake up in the recovery room when your surgery is complete.
- Specially trained nurses and an anesthesiologist will monitor you. They will keep you safe and comfortable while you heal.
- Your care team of specialists will be with you during your rapid recovery journey.
WHAT WILL CHANGE AFTER SURGERY

- You will only breathe through a permanent hole in your neck, called a laryngectomy stoma. This means that you will not be able to breathe through your mouth or nose.
- You will not be able to speak.
- You will not be able to warm, moisten, or filter air.
- You will have a decreased ability to smell and taste.
- You will not be able to blow your nose.

DURING YOUR RECOVERY PERIOD, YOU WILL LEARN TO COMMUNICATE WITHOUT SPEAKING USING:

- Pencil and paper
- Dry erase boards
- Picture boards
- Programs on smart phones
- Gestures

Other options to rehabilitate your voice will come after your hospital discharge when you visit the speech language pathologist.

YOUR STAY AT THE HOSPITAL

What to expect:

- We value your specific needs and we do our best to meet them. If you have a question and we are not by your side, you will be shown how to quickly contact us with a hand-held call system.
- Your blood pressure, heart rate, body temperature, IV fluids and healing progress will be checked frequently.
- Your oxygen levels will be monitored continuously. We will place stickers on your chest to check your oxygen.
- You will have plastic drains in your neck to help your wounds heal.
- Your nurse, physical therapist and occupational therapist will help you begin your rehabilitation.
- Your safety is our biggest priority. We do not want you to fall. If you are alone and want to get up, please contact us with the call light. You will have access to your care team at all times with your personal hand-held call light. Your nurse will show you how this works by simply pushing one button. Even though you will not be able to speak, simply tap on the receiver and a member of your care team will come to your room.

Pain management

We will work with you to best manage your pain. We will ask you to rate the pain you feel after surgery on a scale of 0 to 10 (see chart). Your care team will assess how to best help you feel comfortable and tailor your medicines to meet your needs. It is important to let us know when you first start feeling uncomfortable. Telling us right away will help us keep the uncomfortable feeling from getting worse. Please contact us with the call light any time you need help.

<table>
<thead>
<tr>
<th>Pain Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No Pain</td>
</tr>
<tr>
<td>1</td>
<td>Does not interfere with ADLs*</td>
</tr>
<tr>
<td>2</td>
<td>Mild Pain</td>
</tr>
<tr>
<td>3</td>
<td>Mildly interferes with ADLs*</td>
</tr>
<tr>
<td>4</td>
<td>Moderate Pain</td>
</tr>
<tr>
<td>5</td>
<td>Somewhat interferes with ADLs*</td>
</tr>
<tr>
<td>6</td>
<td>Severe Pain</td>
</tr>
<tr>
<td>7</td>
<td>Partially interferes with ADLs*</td>
</tr>
<tr>
<td>8</td>
<td>Very Severe Pain</td>
</tr>
<tr>
<td>9</td>
<td>Greatly interferes with ADLs*</td>
</tr>
<tr>
<td>10</td>
<td>Worst Possible Pain</td>
</tr>
<tr>
<td></td>
<td>Completely interferes with ADLs*</td>
</tr>
</tbody>
</table>

* Activities of Daily Living (ADL) such as: sleeping, eating, mood, walking, enjoyment of life relationships
Preventing problems after surgery

Movement will help prevent blood clots, pneumonia and pressure sores. Your nurse or therapist will help you sit on the side of your bed to help you move. Every day, you will get out of bed and be active. This movement will help you lessen pain, move blood to prevent a blood clot, and breathe to move air flow to prevent pneumonia. Movement helps you take deeper breaths and creates better air flow to your lungs.

Preventing blood clots

- Your team will determine what treatments to use to help prevent blood clots.
- After surgery and until your discharge, you will receive blood-thinning shots.
- Additional preventative measures may include blood clot-preventing stockings and a special computerized sleeve that helps squeeze your leg muscle to keep the blood moving.
- The nursing staff will encourage you to move your legs, feet and ankles to keep the blood flowing.

Your nutritional needs

- You will have a tube placed in your nose, new stoma, or your stomach.
- You will receive nutrition through the tube, and some medications may also be given through the tube.
- You can expect to have the tube for a minimum of 1 week after your surgery. For most patients, this will not be permanent.
- This feeding tube will be removed once your surgeon has decided it is safe for you to swallow on your own. You may have to do a swallow test before the tube can be removed.

Physical and occupational therapy

After surgery, you will meet with your therapy team. Your physical therapist will work with you on how to get in and out of bed, how to walk, how to climb stairs, and how to do certain exercises safely. Your occupational therapist will assist you in skills for daily activities, like dressing and bathing independently.

Planning your discharge

Our goal is to get you back to your lifestyle safely. As your recovery progresses, your entire care team will be together to discuss when it is safe for you to leave the hospital. Most patients leave the hospital around seven to 10 days after surgery. Together the team will discuss:

- Your progress learning to take care of your laryngectomy stoma
- Your medical concerns
- Your support resources
- Your needs

STOMA AND WOUND CARE

- You will learn to care for the laryngectomy stoma to keep it clean and healthy.
- You may wear a tube (either a tracheostomy tube or similar tube, called a laryngectomy tube) to keep your stoma open. You will have to learn how to remove the tube and clean it to prevent it from clogging with mucus.
- You will have a device to supply humidified oxygen to the stoma in your neck. You need the humidity because you now breathe through your neck instead of your nose and mouth.

We will work with you to determine your care needs at home for a safe recovery and your options for continuing therapy after you leave. Your options include:

- Going home with home-based nursing visits
- A skilled nursing facility or an inpatient rehabilitation facility

Whether you are going home or to a facility:

- Your nurse will bring your discharge instructions from your doctor. Your nurse will review all instructions with you. If you do not understand any discharge information, please ask as many questions as you like so you are confident about what to do when you get home.
- Your nurse will bring you detailed instructions about caring for your laryngectomy stoma.
  
  - Your laryngectomy coach should come to the hospital while you are here. He or she should learn how to clean and care for your stoma, clean any tracheostomy tubes, assist with nutrition, and identify wound complications.

If you are going home, you will be transported in a wheelchair to the patient pick-up at the Barnes-Jewish Hospital south campus main entrance. Someone can meet you there to pick you up.

If you are going to a rehabilitation facility, your social worker or case coordinator will arrange transportation for you.
YOUR JOURNEY HOME

Our goal is for you to be successful at caring for your laryngectomy stoma and ready to return to your lifestyle. In order to be successful, you will have to take good care of your stoma at home.

Home-based therapy

- Your home-based therapy team will plan with you, your surgeon and your laryngectomy coach about how to best recover safely and successfully while home.
- You will have a nurse visit you at your home to understand your healing needs. Your nurse will check your incision, monitor medications and help with wound care.
- You can expect a home health nurse to come to your house on the day of discharge.
- Your home health nurse will visit several times per week.
- A suction machine will be delivered to the hospital before you are discharged. Make sure you know how to use this machine, and make sure the machine is charged before leaving the hospital.
- Your hospital team will send you home with enough supplies to last for a few days. Additional supplies will be delivered to your home as needed.
- If you have any concerns about your home supplies once you are at home, please contact your physician’s office.

Caring for your laryngectomy stoma and laryngectomy tube/tracheostomy tube

- Clean your laryngectomy stoma at least twice a day as instructed by your surgical team. Always wash your hands before and after caring for your laryngectomy stoma. Good stoma care, with hand washing, is key to staying healthy and preventing wound infections and wound breakdown. The skin around your stoma needs to be kept clean and dry.
- You should also clean your laryngectomy tube (or tracheostomy tube) at least twice daily. To clean, first wash and dry your hands. Then gently scrub the laryngectomy tube (or inner cannula of the tracheotomy tube) with a soft brush or pipe cleaner, mild soap, and water. Rinse well under running tap water and pat dry. Insert the laryngectomy tube back into your stoma (or inner cannula back into the tracheostomy tube). Do not clean and reuse plastic inner cannulas.
- If you have a laryngectomy tube or tracheostomy tube, you must keep it free of secretions and mucus. You should suction your laryngectomy tube or tracheostomy tube at least twice daily (or more if you have a lot of mucus). You will need your suction machine, connection tubing, and a new suction catheter each time. Remember to wash and dry your hands first.
- Use suction to remove secretions that you cannot cough out. Suctioning will keep your airway clean and make breathing easier.
- Use humidified oxygen to thin your secretions and moisten the air to allow you to breathe more comfortably.
- Keep a close watch on the skin around your stoma for redness, hotness, odor, increased drainage, opening of the incision or drainage from the incision when you eat or take your tube feeds.
- Follow your surgeon’s instructions on caring for your stoma. You cannot submerge your stoma (in a tub, hot tub, pool, lake, river, etc.)
- Protect your stoma from water. Cover your stoma before you take a shower.
- If the air is dusty or smoky, cover your stoma with a scarf, tie, or specially made cover.

MUCUS PLUGS

- If you become short of breath, remove your laryngectomy tube or tracheostomy tube if you have one.
- Protect your laryngectomy stoma from water. Cover your stoma before you take a shower.
- If the air is dusty or smoky, cover your stoma with a scarf, tie, or specially made cover.
CALL YOUR SURGEON IMMEDIATELY IF:

• Temperature above 101°F or 38.5°C
• The incision becomes red or warm
• There is an opening in your incision
• There is new or increased drainage from the incision
• The drainage from the incision has an odor
• Either calf becomes painful, swollen or tender
• Increasing, persistent swelling of legs or feet
• Increasing pain that is not well-controlled by current pain medication
• If you remove your laryngectomy or tracheostomy tube and you can’t get it back in
• If you have a feeding tube in your neck, stomach or nose and it falls out
• If you have any other concerns

CALL 911 IMMEDIATELY IF YOU HAVE:

• Chest pain/pressure or sharp pain with deep breath
• Shortness of breath that does not improve with removal of tracheotomy/laryngectomy tube or suctioning
• Bleeding from your neck or mouth
• Other life-threatening concerns

Do not drive yourself to the emergency room.

When you return home, have your laryngectomy coach call your local police or fire department to notify them that you cannot speak. They will know to send someone out to check on you if they receive a 911 call from your home.

Pain and medication

Your care team will give you a plan on how to manage your pain when you go home. You have two options to get your pain medication prescriptions filled:

• Go to your regular pharmacy.
• Have them filled by the Mobile Pharmacy at Barnes-Jewish Hospital. This will take the hassle out of getting your prescriptions filled after you leave. Discuss this option with your nurse and the hospital’s in-house pharmacy will deliver your prescriptions to your bedside before you leave the hospital.

Start by taking your pain medication as prescribed. As your pain lessens, take less pain medication.

Constipation (trouble with bowel movements)

• Medication, iron supplements and a decrease in mobility caused by your surgery can cause digestion difficulty and slow down normal bowel movements. Constipation is common, and your physician may prescribe a stool softener for you.

Driving

Have a family member or friend drive you until you feel comfortable to drive on your own. Before you can drive you must be able to:

• No longer be taking prescribed pain medication.
• Feel ready to safely drive.

Your follow-up appointment

You will have a follow-up appointment with your surgeon about 1 week after you leave the hospital to talk about your progress and next steps of your treatment plan. During this appointment your surgeon will:

• Review the results of your pathology with you
• Examine your wounds
• Ask you questions about how well you are following your discharge instructions and recovery plan
• Talk about your daily activities
• Possibly remove any sutures from your skin or any drains in your neck
• Discuss a further treatment plan, which might include radiation therapy or chemotherapy
STAYING HEALTHY CHECKLIST

☐ Provide your body with nutrition

Whether you are taking nutrition by mouth or have a feeding tube in your neck, nose, or stomach, it is important that you get nutrition to heal your wounds.

☐ Stay smoke-free

Being smoke-free means you care about practicing preventive medicine. Also, try to avoid smoky environments. Secondhand smoke can also increase your risk.

☐ Live a healthy lifestyle

Good health is a commitment to knowing your body’s blood pressure, blood glucose, blood cholesterol and weight. Improve your overall health by getting check-ups regularly to live your best health at any age.

☐ Upcoming surgeries

If you are ever in the hospital in the future, remember to tell your doctor that you have had a total laryngectomy and that you only breathe through the hole in your neck.

EQUIPMENT FOR YOUR SUCCESSFUL RECOVERY

☐ Suction machine and tubing

☐ Humidified oxygen

☐ If you go home with tube feeding:

• your feeding tube (in your stomach, neck, or nose)
• cans of tube feeds
• tube feeding pole
• gravity bags
• GU syringes

☐ If you go home with a tracheostomy tube:

• outer cannula
• inner cannula
• obturator
• soft Velcro collar
• spare tracheostomy tube

☐ If you go home with a laryngectomy tube:

• laryngectomy tube
• soft Velcro collar
• spare laryngectomy tube
• humidification valves

☐ Supplies for cleaning your tracheostomy tube or laryngectomy tube (if you have one):

• tracheostomy brushes/pipe cleaners
• small basin or clean bowl
• clean wash cloth
• mild dishwashing liquid soap and tap water
### HELPFUL PHONE NUMBERS

<table>
<thead>
<tr>
<th>HEALTH CARE PROVIDER</th>
<th>NAME</th>
<th>PHONE NUMBER</th>
<th>OPEN HOURS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnes-Jewish Hospital</td>
<td></td>
<td>314-747-3000</td>
<td></td>
</tr>
<tr>
<td>Otolaryngologist Head &amp; Neck Surgeon</td>
<td></td>
<td>314-362-4275</td>
<td>Monday to Friday 8 a.m.-4:30 p.m.</td>
</tr>
<tr>
<td>Center for Preoperative Assessment and Planning (CPAP) Surgery Evaluation Center</td>
<td></td>
<td>314-362-4275</td>
<td>Monday to Friday 7:30 a.m.-4:30 p.m.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Toll free: 800-828-3783</td>
<td></td>
</tr>
<tr>
<td>In-patient therapy services</td>
<td></td>
<td>314-362-2389</td>
<td>Monday to Friday 7:30 a.m.-4 p.m.</td>
</tr>
<tr>
<td>6200 nurses station (The ENT floor)</td>
<td></td>
<td>314-362-4075</td>
<td>24 hours a day</td>
</tr>
<tr>
<td>Barnes-Jewish Hospital outpatient pharmacy</td>
<td></td>
<td>314-362-1224</td>
<td>Monday to Friday 6:30 a.m.-5:30 p.m.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Saturday 7 a.m.-3 p.m.</td>
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<td></td>
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<td>Closed Sunday</td>
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<tr>
<td>Home health agency</td>
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<tr>
<td>Outpatient therapy center</td>
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<tr>
<td>Primary care physician</td>
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</table>

### ADDITIONAL RESOURCES

<table>
<thead>
<tr>
<th>NAME</th>
<th>NOTES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnes-Jewish Hospital Directions and Maps</td>
<td><a href="http://www.barnesjewish.org/patients-visitors/directions-maps">www.barnesjewish.org/patients-visitors/directions-maps</a></td>
</tr>
<tr>
<td>Web Whispers - Throat cancer and laryngectomee rehabilitation</td>
<td><a href="http://www.webwhispers.org">www.webwhispers.org</a></td>
</tr>
<tr>
<td>Head and Neck Cancer Guide</td>
<td><a href="http://www.headandneckcancerguide.org">www.headandneckcancerguide.org</a></td>
</tr>
</tbody>
</table>

For more information, visit BarnesJewish.org and oto.wustl.edu

Barnes-Jewish Hospital
One Barnes-Jewish Hospital Plaza
St. Louis, MO 63110

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GETTING TO KNOW YOUR OTOLARYNGOLOGY HEAD & NECK SURGERY TEAM

Your team’s goal is to provide world-class health care in a compassionate, respectful and responsive way. We are committed to help you during this journey.

Surgeon

Surgeon’s Clinical Nurse Assistant

Anesthesia Team

Registered Nurse (RN)

Speech Language Pathologist

Physical Therapist

Occupational Therapist

Case Manager

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Since 1992, U.S. News and World Report has placed Barnes-Jewish Hospital and Washington University School of Medicine on the elite Honor Roll of America’s Best Hospitals.

To speak with a Washington University otolaryngologist — head & neck surgeon at Barnes-Jewish Hospital, call (314) 362-7509. For more information, visit us at BarnesJewish.org and oto.wustl.edu

Barnes-Jewish Hospital
One Barnes-Jewish Hospital Plaza
St. Louis, MO 63110
Laryngectomy Education Study Exit Survey

Please answer the following questions to the best of your ability. If you prefer not to answer a question, you may leave it blank.

1. Did you receive education with a Speech Pathologist before your surgery?
   - [ ] Yes
   - [ ] No

2. Did your “laryngectomy coach” (caregiver) attend the preoperative education class?
   - [ ] Yes
   - [ ] No

3. How would you rate your level of preparation for trach/stoma care at the time of discharge? Please mark the answer you think is correct.
   - [ ] Not ready at all
   - [ ] Somewhat ready
   - [ ] Ready
   - [ ] Nearly independent with trach/stoma care while in the hospital
   - [ ] Fully independent with trach/stoma care while in the hospital

4. Would you have preferred to receive your stoma/trach/Lary tube care in writing or by video?
   - [ ] No, in person was fine
   - [ ] Yes, in writing
   - [ ] Yes, by video
   - [ ] Yes, in writing and by video
   - [ ] In person, in writing, and by video

5. Do you perform your trach/stoma care by yourself?
   - [ ] Yes
   - [ ] No

6. Have you had problems with your stoma or TEP feeding tube since discharge?
   - [ ] Yes
   - [ ] No

If yes, please describe:

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

Subject Number: ___________________________ Date of Visit: __________/________/_________
7. Have you had to visit an emergency department since discharge from the hospital?
   □ Yes
   □ No

   If yes please specify how many times and for what reasons?
   __________________________________________
   __________________________________________
   __________________________________________

8. Have you had an admission to ANY hospital since discharge from your laryngectomy hospitalization?
   □ Yes
   □ No

   If yes please specify which hospital, dates, and reason.
   __________________________________________
   __________________________________________
   __________________________________________

9. What do you wish someone had told you about this procedure before your surgery?
   __________________________________________
   __________________________________________
   __________________________________________

10. What are your recommendations to improve discharge teaching for trach/stoma care?
    __________________________________________
        __________________________________________
        __________________________________________