

Creating Health Literate Patient Education Materials for Gender Affirming Surgeries

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BACKGROUND

Recognized as a leader in LGBTQ+ healthcare equality and gender affirming healthcare, NYU Langone Health needed patient education materials for its target population. The program serves a diverse, multi-ethnic, multilingual transgender patient population undergoing gender affirming surgery at this large academic teaching hospital.

Currently, none of the available vendor databases at NYU Langone Health provide specific handouts or videos on gender affirming surgeries. The Health Literacy Specialists collaborate with the RN who is the LGBTQ+ Patient Liaison Community Manager, currently one of only a handful of such positions in the country. They convert clinician-authored patient education materials (handouts and video scripts) into plain language, the most effective health literacy best practice.

To date, 8 handouts have been created. Topics include vaginoplasty, phalloplasty and chest surgery.

METHODS

Gender affirming surgeries involve extensive preparation and necessitate a great deal of patient education. They also require a lengthy recovery with needed self-efficacy to manage post-op care.

- Surgeon and RN select needed topics and create first drafts
- Health Literacy Specialists convert documents into plain language, applying health literacy best practices and current research, while following institutional branding guidelines and style guide formatting instructions
- Editing is an iterative process. The editors request clarity on clinical procedure and the clinician authors confirm that plain language conversions are accurate. This process continues until a final version is approved by the clinician authors.
- When drafts become finalized, handouts are formatted into the official patient education template. They are then archived and added to the internal centralized access point (Handouts Document Library). This document library can be retrieved from the Applications Catalog and added to Favorites.
- Video scripts are advanced to the proper point person for the next steps in production. Translations are arranged on demand.

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PLAIN LANGUAGE CONVERSION – BEFORE AND AFTER

Dilation Instructions Post-After Vaginoplasty

Please follow these steps carefully for dilation after your vaginoplasty:

- Clean your dilator with warm water and antibacterial soap. Rinse well and dry with a clean paper towel or cloth. **(Do not use alcohol wipes. Do not put dilator in dishwasher.)**
- Set up your supplies:
 - ✓ Dilator
 - ✓ Lubricant
 - ✓ Mirror
 - ✓ Baby wipes
- Wash your hands, **and have your supplies set up (dilator, lubricant, mirror, baby wipe)**
- Apply lubricant to your dilator **prior to insertion before inserting it.** Only use water-based lubrication. Avoid silicone-based lubricants. Do not use Vaseline.
- Lie on a towel, flat on your back with only **15 degrees of elevation.**
- Take **ten-10** deep breaths to relax.
- Use the hand mirror to **identify** find your vaginal opening. Gently insert the dilator into **the your** vagina at a slightly downward angle of 15 degrees. **Insert** until **the dilator is** under **your** the pubic bone. Then **continue keep** inserting straight inward. Aim towards **your** the belly button.
- You may feel a **small amount of light** resistance and tenderness. Stop if there is too much resistance or **severe-very bad** pain. Try a smaller dilator, **if possible.**
- Insert** the dilator to the full depth of **the your** vagina. **You will know you have reached this when** **(until** you feel moderate pressure or resistance, **and hold** in place for 15 minutes. Apply firm pressure, but **do not** not forceful.
- 10. Wash your dilator** After each use, **use the soap and water to** Use soap and water, **cleanse the dilator with soap and water, and dry** thoroughly well. **Dry well.**

Dilation Instructions Post Vaginoplasty

Please follow these steps carefully for dilation after your vaginoplasty:

- Clean your dilator with warm water and antibacterial soap. Rinse well and dry with a clean paper towel or cloth. **(Do not use alcohol wipes. Do not put dilator in dishwasher.)** Wash your hands and have your supplies set up (dilator, lubricant, mirror, baby wipes).
- Set up your supplies:
 - ✓ Dilator
 - ✓ Lubricant (water-based only)
 - ✓ Mirror
 - ✓ Baby wipes
- Wash your hands.
- Apply lubricant to the dilator before you insert it. Make sure lubricant is water-based (K-Y® Jelly or Surgilube®). Avoid silicone-based lubricants. If it is silicone-based, it will say so on the container. Do not use Vaseline®.
- Lie on a towel, flat on your back with only 15 degrees of elevation.
- Take 10 deep breaths to relax.
- Use your hand mirror to find your vaginal opening. Gently insert the dilator into your vagina at a slightly downward angle of 15 degrees. Insert until the dilator is under your pubic bone. Then keep inserting straight inward. Aim towards your belly button.
- You may feel a slight amount of resistance and tenderness. Stop if there is too much resistance or severe pain. Try a smaller dilator, if possible. For example, if the doctor instructed you to move up to the blue dilator, return back to the purple dilator and start again.
- Insert the dilator to the full depth of your vagina. You will know you have reached this when you feel moderate pressure or resistance. Hold in place for 15 minutes. Apply firm pressure, but do not force.
- Wash your dilator after each use. Use soap and water. Dry well.

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Created: 08/2017

EVOLVING HEALTH LITERACY BEST PRACTICES

- **Images**
Research suggests that images help patients follow instructions. However, high quality copyrighted images are often cost prohibitive. For this reason, the RN takes relevant photos (e.g., incision care, and scar management and drain care) to include in the patient education handouts as visual aids.

- **Readability Levels and Other Criteria**
While readability formulas remain important tools for assessing health literate materials, there is a shift away from using them as the primary focus. The trend is toward using other criteria that go beyond simply using algorithms which count syllables and paragraphs to gauge grade reading levels. Examples are:
 - ✓ word choice & style - address patient as “you” for active voice and gender neutrality
 - ✓ content actionability - start each instruction with an action verb and limit key messages
 - ✓ layout & design - use headings and subheadings, bulleted lists and include plenty of white space
 - ✓ numbers - express in numeric form
 - ✓ organization - put the most important information first
 - ✓ visual aids - include relevant images that enhance the content

RECOMMENDED RESOURCES

Below are some of the resources we refer to when working on health literate, culturally sensitive materials for patients and families of the NYU Langone community, including our transgender patients:

- **A Progressive’s Style Guide** (especially the section on gender): SUMOFUS_PROGRESSIVE-STYLEGUIDE.pdf
- **Everyday words for Public Health Communication**, a plain language glossary from the CDC - www.cdc.gov

- **Plain Language.gov** - an online resource with tips and word suggestions - plainlanguage.gov/
- **The Institute for Healthcare Advancement’s listserv**. This listserv community - which includes clinicians, community health workers, educators and others working in the field of health literacy - is a valuable source of information, ideas, best practices and emerging trends. Sign up at: ihahealthliteracy.org