

Colonoscopy : What I need to know

HEALTHCARE ACCESS FOR AUTISM PROJECT
MADE POSSIBLE BY THE C.J.L. FOUNDATION

 LURIE CENTER FOR AUTISM
Mass General Brigham



Tips for Using this Social Story

▶ **Review in advance.**

- ▶ Plan to review the social story for yourself or with your loved one well in advance of the colonoscopy. This allows time to process expectations, identify possible challenges, and problem solve ways to help decrease anxiety.

▶ **Individualize.**

- ▶ Every individual may need or prefer different amounts of information, so decide what information is most helpful to you/your loved one.
- ▶ Add pictures or information that is specific to you/your loved one (e.g. picture of doctor, support person, preferred distractions). There are several areas throughout the story where information can be edited and personalized.
- ▶ For individuals with more cognitive or communication challenges, it may be helpful to focus more on the sections of “How do I prepare for a colonoscopy?” and by looking at the pictures of “What happens on the day of a colonoscopy?” Suggested slide numbers for individuals with more cognitive or language challenges: Slides 4-5, 12-14, 19, 24 -37

Tips for Using this Social Story

▶ Identify Coping Strategies.

- ▶ Look for coping strategies that are **highlighted in yellow** throughout the story. Identify tools that may be helpful to decrease anxiety. Distraction is the number one strategy to decrease anxiety around medical procedures.

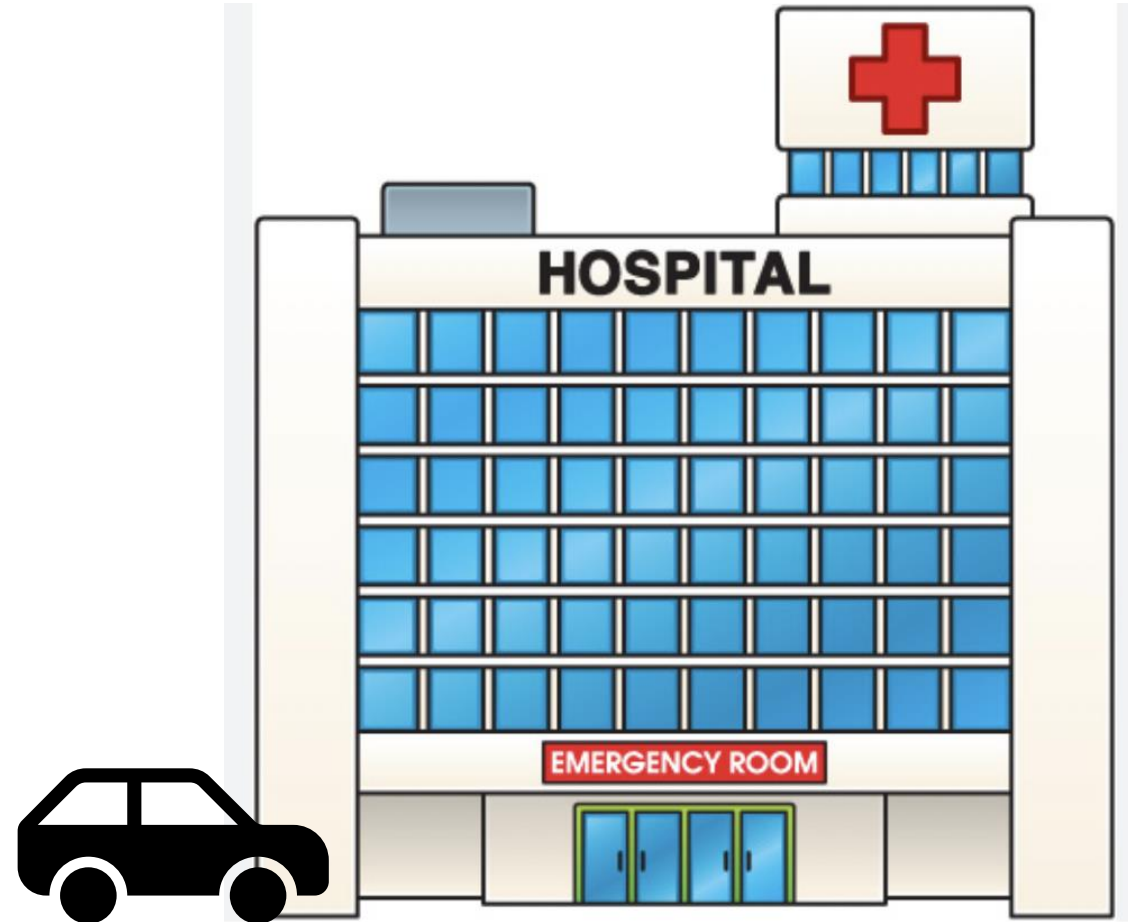
▶ Advocate.

- ▶ You know yourself/your loved one's needs the best. Advocate for what you need to help make the colonoscopy successful. Sometimes this may include using visual supports to preview expectations, having a support person available before and after the procedure, optimizing sedation time by coordinating other care that needs to occur, etc.
- ▶ Consider making a list of questions for your doctor/medical team that you/your loved one have about the colonoscopy or related outcomes.

My doctor, _____, said I need to have a colonoscopy. This is an important procedure to keep me healthy.

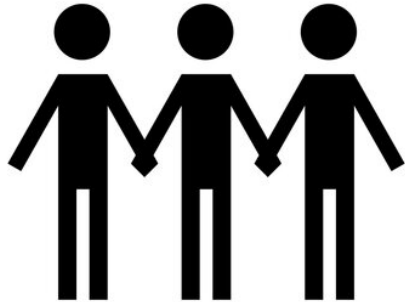
On _____ (date) at _____ (time), I will be going to _____ to get a colonoscopy.

My doctor: _____

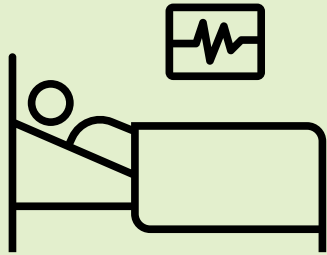



I may feel nervous, but it's okay because my family member/caregiver will go with me. I will not be alone.

First, I go to the hospital. Then, when the colonoscopy is over, I will go home.



_____ will come with me

FIRST HOSPITAL	THEN HOME
 An icon of a hospital bed with a patient lying in it, and a monitor displaying a heart rate line above the bed.	 An icon of a simple house with a chimney and two windows.

Why do I need a colonoscopy?

A colon is also known as the large intestine. It is important for how our body makes and stores poop.



Poop/Stool

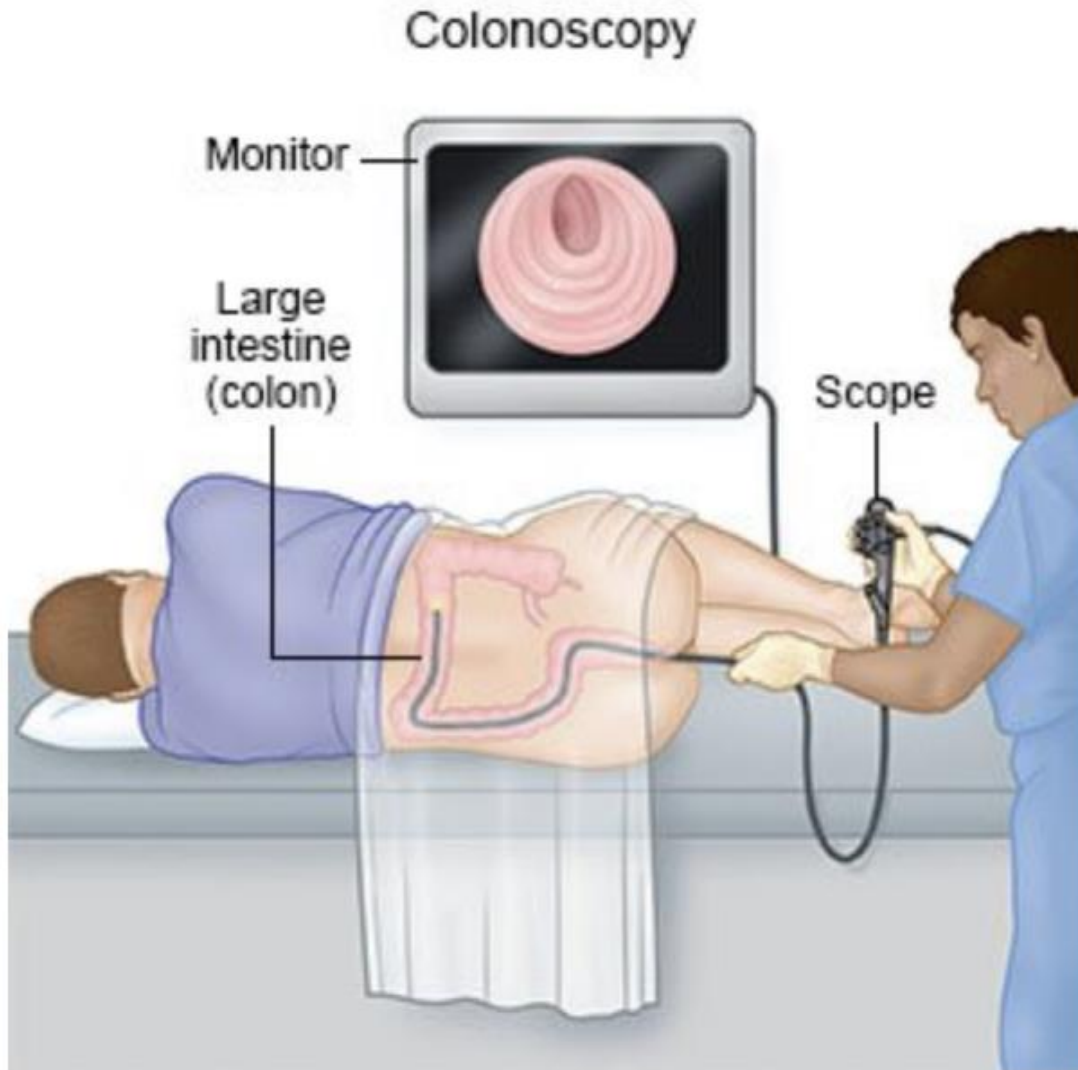


Image from: <https://www.drugs.com/cg/colonoscopy.html>

A colonoscopy is a safe procedure that allows my doctor to look at my colon to check that it is healthy. My doctor will use a special camera called a Colonoscope to look inside my colon (this is also called the large intestine).

It will not hurt. I will be asleep during the colonoscopy. My doctor will give me medicine to help me feel comfortable.

It is an important procedure to look for and sometimes treat stomach problems, like polyps or tissue growths that are not healthy for my body. These can be removed during a colonoscopy. It will not hurt.

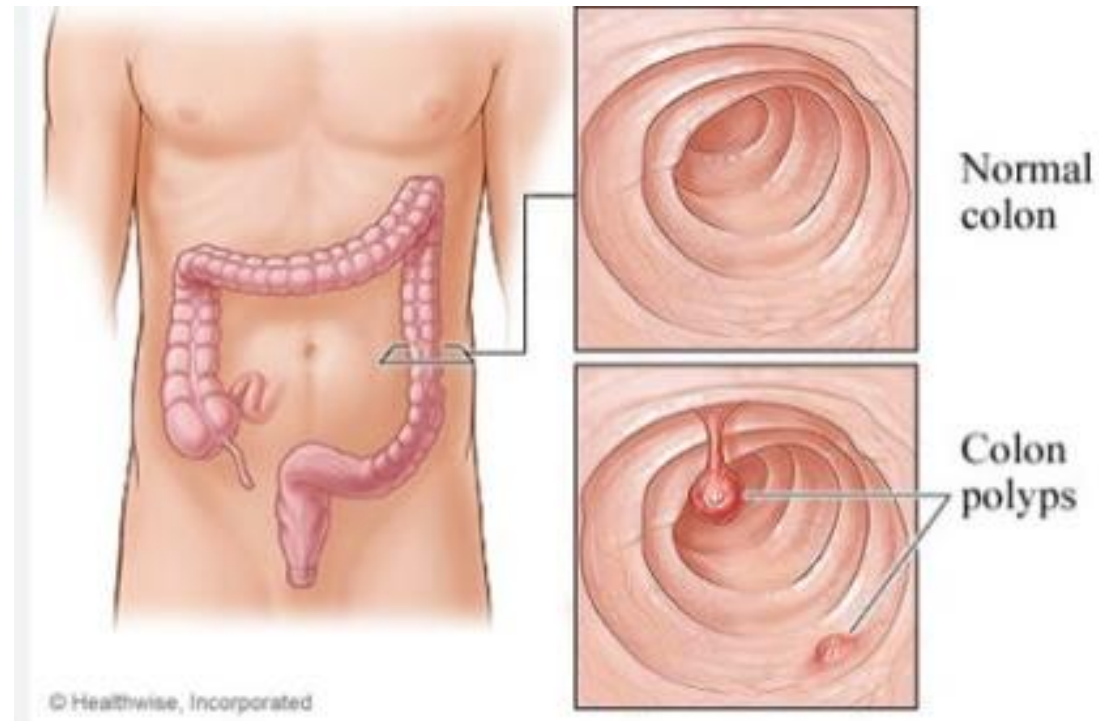
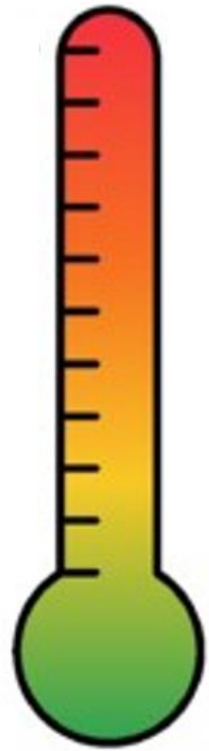


Image from <https://www.uvmhealth.org/healthwise/topic/tp12114>

How do I get ready for a
colonoscopy?

I may feel nervous or scared.
This is normal.

If I am feeling scared, I can:



I Feel
Very Scared

I Feel
a Little Scared

I am not
Scared/ Feel
Okay



<p>Tell someone how I am feeling</p>	<p>Ask my nurse or doctor a question</p>	<p>Take a deep breath</p>
<p>Think of something fun I will do when I am done</p>	<p>Watch a video or look at pictures</p>	<p>Other</p> <p>_____</p> <p>(insert other)</p>

I will start to get ready for my colonoscopy several days before my procedure. This is called the “Prep” and includes taking medicine, drinking fluids, going to the bathroom, following a specific diet, and preparing to go to the hospital/clinic where I will complete the colonoscopy.

It is very important I follow the doctor’s instructions. If I do not follow these instructions, I may have to reschedule or do a colonoscopy again.

I will need to:

✓ Take medicine

✓ Go to the bathroom more than usual

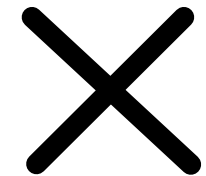
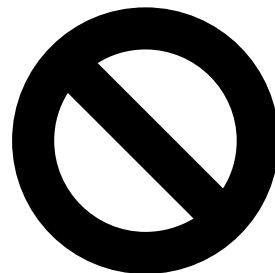
✓ Eat foods I can have

✓ Drink a lot of fluids



I should NOT:

▪ Eat or drink foods my doctor says not to eat





First, I must NOT eat foods that my doctor says I cannot have beginning on _____ (day specified by doctor).

My doctor and family can help me make a plan for what I CAN have.




When I am done with my colonoscopy, I can eat my favorite foods again.







Whole Grain/Whole Wheat Bread	Oatmeal
	

Veggies or fruits, Canned/Cooked without seeds or skin
 



Popcorn	Seeds/Nuts	Salad
		

White Bread	Pasta/Noodles	Soft, well cooked meat, chicken or fish
		

Corn	Beans	Raw Fruits/Vegetables
		

Potatoes, No Skin	Eggs
	

I can talk to my doctor and family to make a list of what I can eat. I may be able to enjoy some of my favorite foods.

Some of my favorite foods I can have include:

-
-
-



A few days before my colonoscopy on _____ (date), my doctor may tell me to take some anti-gas pills (e.g. Mylanta Gas, Maalox Anti-Gas, Gas-X) around dinner time. This medicine is important because it prevents bubbles from forming in my colon so my doctor can see better.



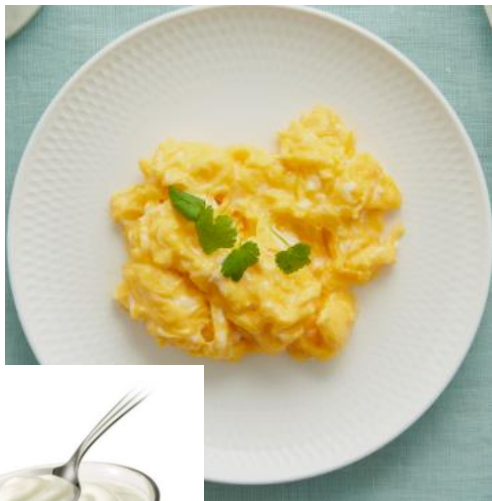
One day before my colonoscopy on _____ (date), I can have a SMALL breakfast, but then I must ONLY drink clear liquids for the rest of the day.

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Foods/Drinks
I can have



First, I can have a small breakfast



Then, I can ONLY drink clear liquids the rest of the day, like:



- Gatorade
- Water
- Ginger Ale
- Broth
- Popsicles (not red)
- Apple juice or white grape juice
- Pedialyte

One day before my colonoscopy on _____ (date), I should NOT drink liquids that are red, purple, or orange. I should NOT eat solid food, dairy, or drink alcohol. This may feel difficult, but I can do it and will be able to have the things I like when I am done.

Foods/Drinks
I cannot have



Liquids that are Red, Purple, or Orange	Solid Food	Dairy	Alcohol
			

If I feel hungry, I can:

- Drink a clear liquid that I CAN have
- Do something I enjoy to help me think about something else
- Think “I can do this” and remember I will be able to eat the foods I like when I am done

In the afternoon the day before my colonoscopy on _____ (date), I will need to drink a lot of liquid with medicine in it (e.g., Miralax, Magcitrate, Go Lightly). This will help me go to the bathroom a lot, which helps the doctor have a clear picture of my colon. Sometimes this can make me feel nauseous or bloated, like my stomach is full.



If I feel nauseous or full, I can:

- Take a break from drinking
- Drink small amounts at a time
- Do something I enjoy while drinking to help me feel calm
- Think "I can do this" and remember I will be done soon
- Rest my body

First, I will drink a lot of liquid, then I will need to go to the bathroom often. This can cause me to pee/urinate frequently and cause me to have many bowel movements.



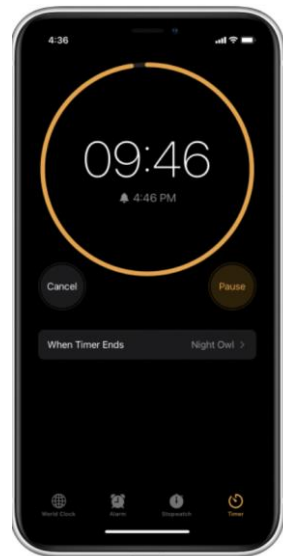
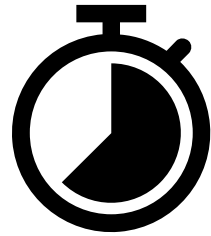
I can keep track of how much I am drinking on a chart.

I can set a timer to remind me when I need to drink more.

My goal is to
drink this
much:

20

_____ cups



TIME	DRINK (AMOUNT)	FINISHED? <input checked="" type="checkbox"/>

My poop should eventually appear clear, yellow liquid. Going to the bathroom often can cause my butt to feel irritated, hurt, or burn.



My poop should eventually appear like clear, yellow liquid



If my butt feels irritated, hurt, or burns, I can:

- Use baby wipes
- Use Vaseline
- Put cream on my butt to help me feel better



I may be able to drink liquids until a certain time. The doctor will tell me when to STOP eating and drinking (sometimes this is called NPO). After this time, I CANNOT eat or drink, because if I do, my colonoscopy could get cancelled.



After

at

_____ (date)

_____ (time)

It can be hard not to eat or drink. I may feel frustrated or hungry. To help me feel better, I can:

- Think "I can do this"
- Remember I will be able to eat and drink the things I like soon
- Watch TV or a movie
- Do something I enjoy like _____
- Talk to my family/friends
- Other _____

What happens the day of my colonoscopy?

I will arrive at the hospital with my family/support person.
I will take the elevators up to the floor I will have my procedure.



I will check in at the front desk and wait for the nurse to call my name.

I can bring some things I like to do to help me relax while I wait.



I can bring things I like to help me relax, like:

- Phone/Video



- Book



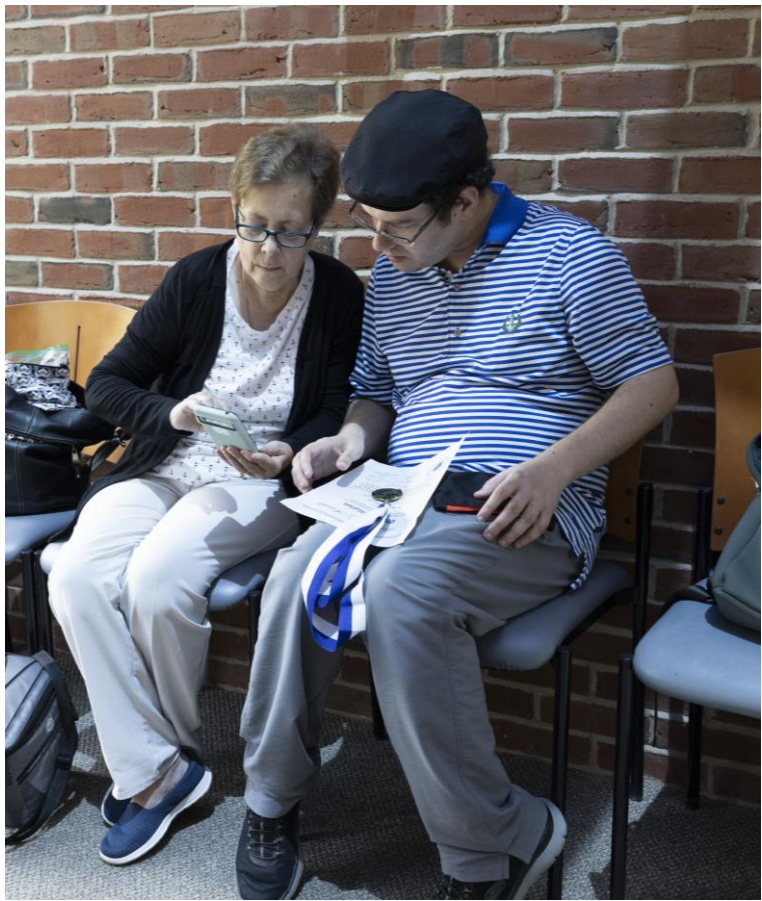
- Other _____
(insert preferred activity)



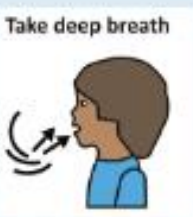


Next, I will go to a room to wait for my doctor and get ready for my colonoscopy.
I will change into a hospital gown, comfortable socks, and take off any jewelry.
I will have a pillow and warm blanket.

I will wait here until it is time to start the colonoscopy, for about 30 – 60 minutes.



It can be hard to wait, but while I wait I can try to stay busy by doing things that help me feel relaxed.



Tell someone how I am feeling	Ask my nurse or doctor a question	Take a deep breath
		
Think of something fun I will do when I am done	Watch a video or look at pictures	Other <hr/> (insert other)
		

My nurse will take my vitals, like measuring heart rate, temperature, and blood pressure. They will put leads on my chest that will measure my heart rate. This doesn't hurt and helps my doctor and nurses know more about my body.



The nurse will measure my heart rate by putting a pulse ox on my finger. It will feel like a little squeeze.



The nurse may put a thermometer on my head to take my temperature



The nurse may put a blood pressure cuff on my arm to take my blood pressure. It is a tight squeeze.



The nurse will put leads, or small stickers, on my chest. They stay on to measure my heart rate.

My doctor and nurse will come to see me and ask me questions and answer any questions I have. I can make a list of questions ahead of time.

My doctor: _____



Insert picture of doctor



Questions I would like to ask my doctor: Insert questions

1.

2.

3.

My doctor is going to use medicine called anesthesia to help me sleep and feel comfortable during my colonoscopy. To help me get to sleep, I will need an IV.

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An IV includes a small needle and leaves a small tube in my arm or hand. When the nurse puts it in my arm, I may feel a little pinch, but it will be done quickly. This is important to give me medicine and make me comfortable.



If I feel nervous, I can:

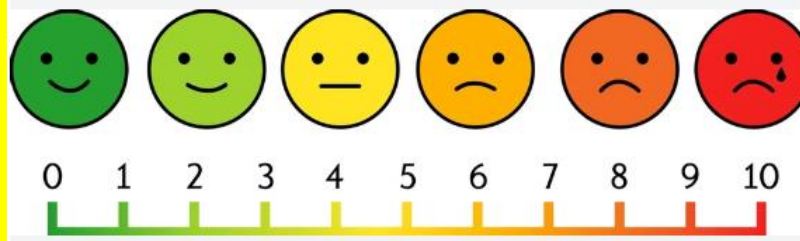
- Take a deep breath
- Look away from the needle
 - Watch a video
 - Look at pictures
- Talk about something with my nurse/family member
- Tell someone how I am feeling

It is normal to feel nervous. If I feel nervous, there are several things I can do to help me feel calm. Distraction can be very helpful to keep me calm.

Take a deep breath



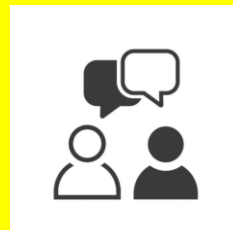
Tell someone how I am feeling



Look away from the needle



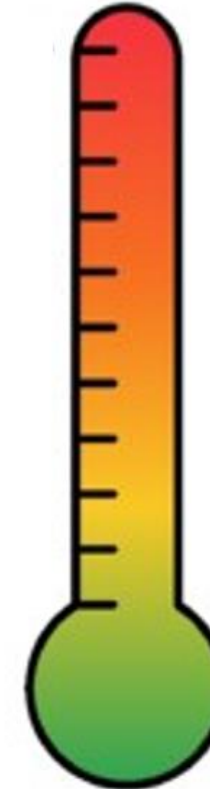
Talk about something with my nurse/family member



Watch a video or look at pictures



OTHER:



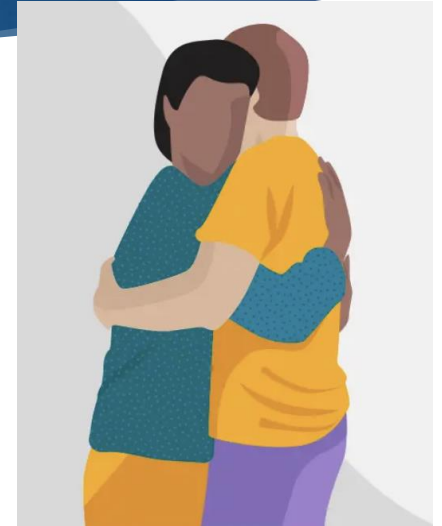
**I Feel
Very Scared**

**I Feel
a Little Scared**

**I am not
Scared/ Feel
Okay**

When it is time for my colonoscopy, I will get ready to go to the operating room. I will lay on the rolling bed and my nurses will stay with me.





I will say "See you later" to my family or support person; they will be in the waiting room. I will see them soon.



I will go to the operating room. This is where I will lay on a table on my side. I may see a lot of tools or equipment. The procedure should only take about 30 – 45 minutes.

If I feel scared, I can close my eyes. The room may feel cold; I can ask for a blanket.



If I feel scared	Then I can close my eyes.
	
If I feel cold	Then I can ask for a blanket.
	

Sometimes it can be hard to get an IV. My doctor may give me medicine through a mask to help me get to sleep before putting an IV in my arm.

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The mask is plastic, smells like plastic, and will cover my nose and mouth and press on my face. The mask will help me breathe in air that will make me sleepy.

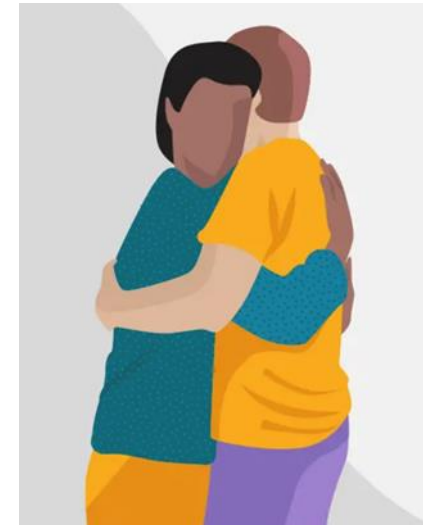


If I feel nervous, I can:

- Take a deep breath
 - Close my eyes
 - Watch a video
 - Look at pictures
- Talk about something with my nurse/family member
- Tell someone how I am feeling

When the procedure is finished, my doctor and nurses will take me to a “recovery” room to rest. My family/support person will be there to see me.

This is where I will rest for a bit and my doctors and nurses will check to make sure I am feeling okay and help me get ready to go home.



My nurses will take my vitals again to check to see how I am feeling. When my nurses say my vitals are back to normal, I can get ready to go home.

My nurse will take out my IV, which has some tape that may feel sticky, but there is no needle.



The nurse will measure my heart rate by putting a pulse ox on my finger. It will feel like a little squeeze.



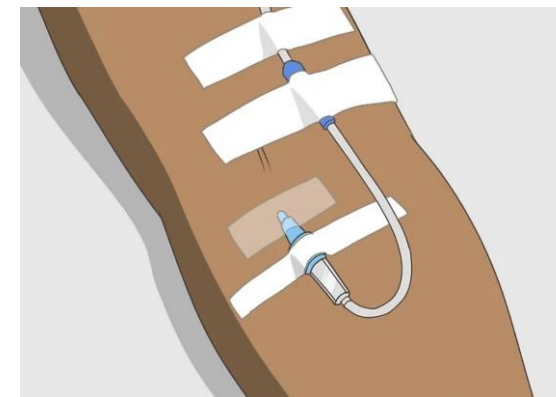
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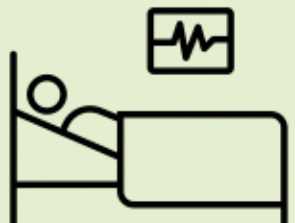

The nurse will put leads, or small stickers, on my chest. They stay on to measure my heart rate.

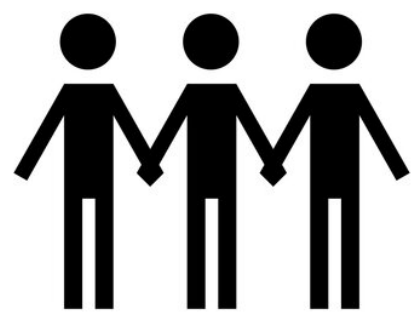


The nurse will take off the tape and my IV. There is no more needle.

When my doctor and nurses so it is okay, I can go home and relax the rest of the day.

I will need a friend or family member to drive me home.

FIRST HOSPITAL	THEN HOME
	



_____ will drive me home.

(insert picture of support person)



Once I am home and my body feels ready, I will be able to go back to eating, drinking, and taking medicines like I normally do. I may feel tired for a while – this is normal.

I could do something fun or relaxing that I enjoy to celebrate being done with my coloscopy.



Something fun I could do to celebrate being done with my coloscopy is:

- Plan a special meal
- Do a fun activity
- Visit someone special
- Other _____

My doctor and nurse will give me instructions to follow when I get home. It is important to follow these so I can recover and feel better soon.



Sometimes, I may see blood in my poop for a few days after a colonoscopy. This happens if my doctor needed to take out polyps or tissue growths. This is normal.

My butt may hurt for a few days and I might have gas or feel bloated. There are things I can do to help me feel better.

If I see blood in my stool,



I can:

- **Know this is normal for a few days after my colonoscopy**
- **Ask my doctor if I have questions or I am concerned**

If my butt hurts after my colonoscopy,



I can:

- **Use wipes or cream**



Something fun I could do to celebrate being done with my colonoscopy is:

- Plan a special meal
- Do a fun activity
- Visit someone special
- Other _____

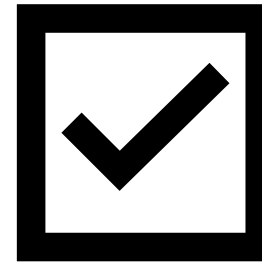
Soon, my doctor will talk to me and my family about the results of my colonoscopy and discuss anything I need to know. Usually, the doctor will say I do not need to have another colonoscopy for several years.

My doctor, _____,

(insert picture of doctor)



will talk to me and my family about the results and tell me what I need to know.



**My colonoscopy is
ALL DONE!**

**It was good I did
something that
helps me to stay
healthy!**

Made possible by the C.J.L. Foundation

Additional Social Stories focused on adult preventative care procedures can be found at
<https://www.massgeneral.org/children/autism/lurie-center>



LURIE CENTER FOR AUTISM

Mass General Brigham