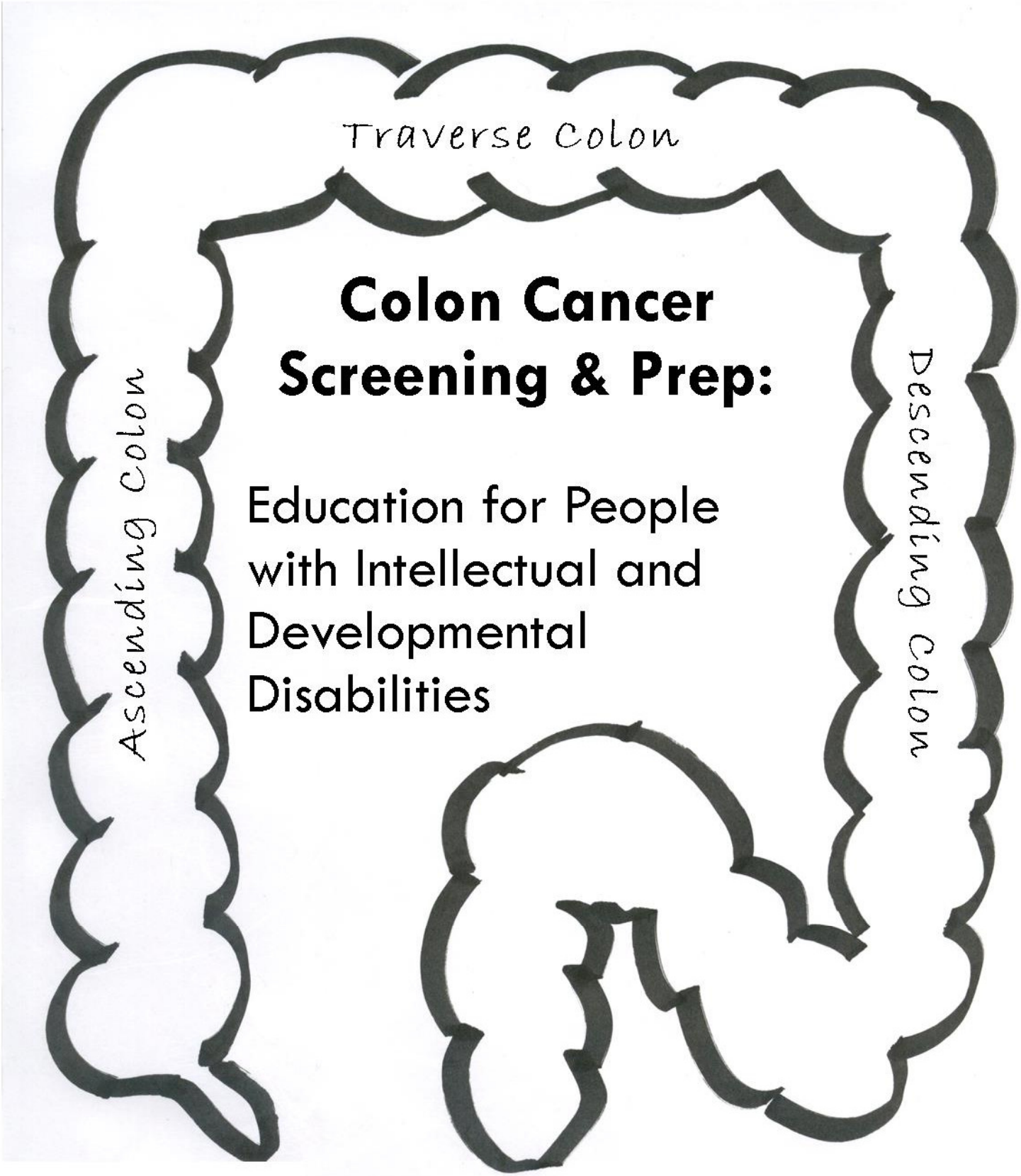

Colon Cancer Screening & Prep:

Education for People with Intellectual and Developmental Disabilities

ARKANSAS DISABILITY & HEALTH PROGRAM

Instructor's Manual

Colon Cancer Screening & Prep:
Education for People with Intellectual and Developmental Disabilities

Instructor's Manual

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Instructors Overview of the Curriculum

Purpose

This curriculum was designed with the intent to educate individuals with intellectual and developmental disabilities about the importance of their participation in their own health care. The preparation for colorectal cancer screenings are difficult to perform. It is our hope that understanding the purpose of the screening will lead to better adherence of the preparation protocol. This ultimately then will lead to more effective screenings. This curriculum uses hands-on activities, audio and video models and role modeling to support the learning process.

Participants

The Colorectal Cancer Screening & Prep curriculum was designed specifically for adults with intellectual and developmental disabilities, including those with mild to moderate intellectual disabilities. The participants must possess sufficient receptive and expressive communication skills to understand the instructional material and participate in the class.

Adults who wish to participate in this class are voluntary participants. No one should be forced into attending the class. Coercion diminishes the rights of the individual and detracts from the learning of other adults. At any point in the class, participants can choose to stop attending the class of their own free will.

Class size should be no more than 16 individuals. This allows for good discussion, decreases the chances that someone can monopolize the group, and allows for breakouts in smaller group activities. Consistent class attendance is very important for learning and maintaining group cohesion.

Instructor

It is recommended that instructors of this curriculum view the trainer's class in person or archived online on the Arkansas Disability and Health website. Instructors should be accustomed to working with adults who have intellectual and developmental disabilities and should have experience in leading groups. It is very important that the instructor is capable of reading group dynamics to avert inappropriate discussions or actions that may derail the class. Instructors should also be able to encourage group participation, listen, and be able to create or advocate for a supportive learning environment. The instructor should be comfortable with their own bodies and be able to coordinate class activities and effectively communicate the educational topics introduced.

Class Environment & Atmosphere

The classroom should be large enough to accommodate classroom seating for 16 with room to accommodate activities and wall charts. Group discussion occurs best when the group is closer together at one table or several tables close together. The class should be in a location where others do not need come in and free from outside distractions such as other activities, or electronic devices.

Class participation and retention of the educational information will be best received in a fun, pleasant, supportive environment. Participants should feel free to share questions and concerns with everyone in the room.

Medical Follow Up

If a member of the class reports blood in their stool or any other symptom of possible illness, the instructor should privately talk with that individual and their staff and or family members (as appropriate) to encourage medical follow up.

Class Schedule

The class is divided into four weekly 60 minute classes. Days and times for the classes should be scheduled to accommodate students as much as possible. If the class is held during normal work hours, a commitment must be made by the participants and their employers so individuals can be freed from their work responsibilities during the class time.

Colorectal Cancer Screening & Prep Training Kit

Through funding from the Arkansas Cancer Coalition, this training was developed and the audio and visual tools used in this training were purchased to create 4 training kits that can be checked out by Nurses or other Developmental Disability Provider staff to conduct this training for the individuals with IDD served in the community. The kit includes:

- CD Rom of Trainer's Supplies
  - Letter to Staff or Family Approving Class participation
  - Sign In Sheet
  - United States Preventive Services Taskforce Screening Recommendations for Men and Women
  - Leaves or Apples for Family Medical Tree Activity
  - Digestive System Color Sheet
  - High Fiber Food Handout
  - Low Fat Food Handout
  - Colon Cancer Handout
  - Attendance Certificates
- Flip Chart Paper
- Markers
- Pens
- Glue Sticks
- 16 Participant Folders
  - United States Preventive Services Taskforce Screening Recommendations for Men and Women
  - Leaves or Apples for Family Medical Tree Activity
  - Digestive System Color Sheet
  - High Fiber Food Handout
  - Low Fat Food Handout
  - Colon Cancer Handout
- Digestive System Wall Chart
- Colonoscopy vs Sigmoidoscopy Poster
- Polyp Models
- Bingo Game
- Fecal Occult Blood Test Kit
- Colonoscopy Prep Kit
- Hospital Gown
- Balloons

Colon Cancer Jeopardy Game
Graduation Gifts: (awareness bracelets, blue ribbons, water bottle)

Kits can be checked out free of charge by contacting Vanessa Smith at vanessas@uark.edu or calling (501)-682-1666. Kits can be kept for 6 weeks and will include return shipping postage. We need a copy of the completed sign in sheet to document need and use to our funder.

Class Preparation

Each class requires supplies, audio visual materials and instructor preparation. Prior to each class, the instructor should have the supplies needed for the day. Each class indicates the supplies and set up required. Supplies are available in the Colorectal Cancer Screening & Preparation Kit.

Handouts & Other Resources

There are several handouts and games that support the presentation of the educational material. Instructions for each game are included in the Instructors Manual or Trainer's Kit as well as all game supplies. If the instructor identifies another resource for information or activities that enhance learning, they should share that with the Arkansas Disability and Health Program. This will allow our program to share additional resources regarding this important educational topic.

Instructional Content

The Instructor's Manual is set up by class with four classes of 60 minutes each. The beginning of each class identifies the supplies needed to conduct that class. All supplies can be found in the training kit.

Class 1

Introduction and Overview for Colon Cancer Education

Supplies Needed:

- Sign In Sheet
- Flip Chart Paper
- Markers
- Class Schedule
- Crayons
- Pens
- Glue Sticks
- Participant Folders
  - Screening Recommendations Handout
  - 11x17 Paper
  - Leaves/Apples

1. Introductions

Introduce yourself, welcome the class members, and lay out the framework for how the class will flow.

Introductions may not be necessary if the leader knows everyone in the class and the class members know the leader. However, it cannot hurt.

2. Overview

In this class, we will learn about how to better take care of our health. The topic of this class is colon cancer screening. You have all probably heard of cancer or know someone who has had cancer. There are different types of cancer that can develop in any part of the body. This class is going to focus on colon cancer. The colon is a part of our digestive system and is near our stomach. We are going to learn more about that in this class.

Let's start with an overview of when we are going to meet, how often, and some rules for our class.

We are going to meet _____ for the next _____ days/weeks/months, etc.

Post a flip chart page with meeting dates and times in the class area.

A list of our class days and times are available and has been shared with your family and staff.

Let's look at what kind of rules we want to have for our class. When a group of folks spend a lot of time together it is good to know what to

expect. So to make sure we all do what is expected we are going to come up with our list of group rules. We all have rules we have to go by. We have rules if we are driving, working, or living with others and it's a good idea to have a list of rules when a group of people get together in a class like this. Since this is your group and you are here because you want to learn how to take care of your body, how about you come up with the rules you want everyone to follow?

I have one rule I want to suggest.

This class is voluntary. That means no one has to be here. We want you to learn and this is a way to do that, but staff are not going to make you come or stay in this class if you want to leave.

Ok, now what kind of rules do you want to have for you class?

Some groups have problems coming up -at least initially- with rules. This is where you can help.

Do you think we all need to shout out our answers at the same time? Maybe we should

have one person speak at a time? Is that a rule you would like to have?

Typically we have rules like:

1. Confidentiality – stories shared by one person are their stories only. Other people cannot share the stories their classmates tell in class. Only I can share my stories.
2. Be nice to each other.
3. No hitting, pushing, etc.

Write the rules on a piece of flip chart paper and post them during each class session. It is also a good idea to review them at the beginning of each class. If someone is not following a particular rule, the leader can identify the rule not being followed and ask if the group has changed their mind and want to get rid of that rule. However, you as the leader must be willing to get rid of that rule if the group wants it gone. So don't offer to remove rules you as the leader want to keep.

3. Being a Healthy Adult

As an adult there are things we do to keep our bodies healthy. Can anyone name something they do to stay healthy?

Group discussion, list responses on flip chart paper.

There are tests we have to do throughout our lives that check for any new or growing diseases in our body and make sure we are healthy. Can anyone name any of these tests?

Some common responses can be:

Immunizations – to keep us from getting some diseases
Dental Checkups – take check our teeth and gums
Blood work – to check our sugar and for signs of infection
Mammogram – breast cancer
Pap Smear – cervical cancer

Pass out the United States Preventive Services Taskforce Screening Recommendations. Review briefly some of the more common screenings.

Whose job is it to keep us healthy?

- As an adult it is our job to keep our body healthy.
- Staff and family members can help us.
- Our doctor can also help us stay healthy.

In this class we have only one piece of homework and here it is. It is important to know what medical

conditions our family members have experienced. This is called a family medical history. Whenever you go to the doctor, they may ask you if you have a family history of a certain disease and you need to know. This will help the doctor keep you healthy.

Make available the Family Medical Tree supplies (card stock paper, apples or leaves handouts will be in their participant folders and pass out crayons, scissors, and glue sticks). Encourage participants to work with the staff or family members to fill it out the medical information. In class, put the tree together identifying immediate family members (siblings, parents, aunts & uncles, grandparents).

Work with the Nurse or Case Manager on this task as they typically have knowledge or contact with family. This homework may involve calling family members to make sure the information is complete and accurate. There is an instruction sheet available to provide staff completing medical information of the tree.

Review a completed Family Medical Tree with the group as an example of how to fill out the form.

Class 2

The Colon and its Job in the Digestive System

Supplies Needed:

- Sign In Sheet
- Rules
- Class Schedule
- Digestive System Wall Chart
- Crayons
- Diseases of the Digestive System Poster
- Bingo Game
- Participant Folders
    - Digestive System Coloring Sheet
    - High Fiber Foods Handout
    - Low Fat Foods Handout

Review the class purpose, schedule and rules. Pass around the sign in sheet for participates to check off their attendance.

Today we are going to start talking about the colon. The colon is part of the digestive system in our body. That means it helps the body with the break down

and absorption of the food we eat so that our body can use it or get rid of what it cannot use.

So let's start with the digestive system…

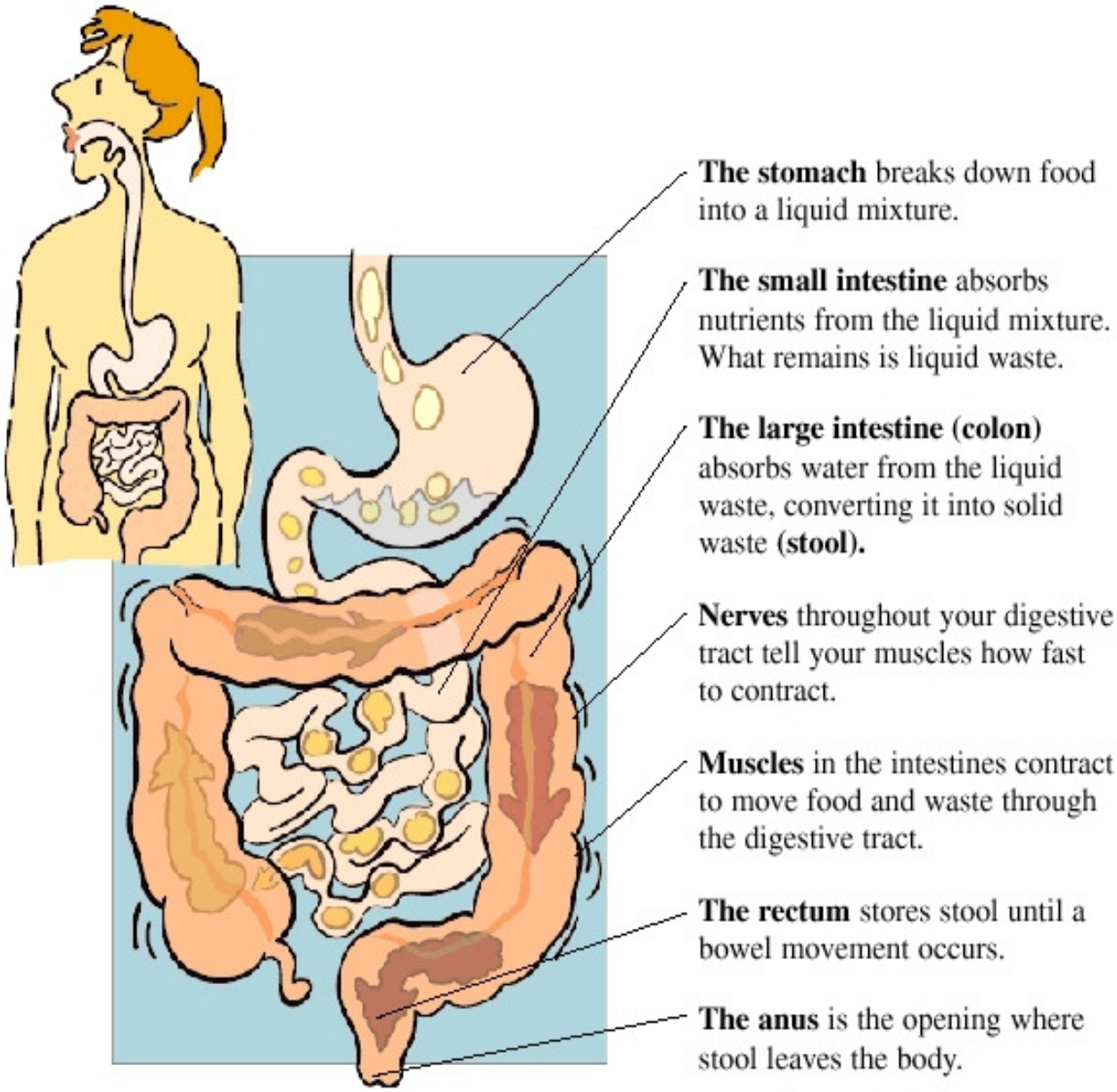
From the first bite of food you take, digestion begins. Your teeth break the food down into a mush and then it moves down to the stomach.

Let's look at our handouts of the digestive system.

Have the participants get the Digestive System Coloring Sheet out of their participant folders and make the crayons available.

Point out each of the parts of the digestive system and discuss what each part does to complete digestion.

Have participant color the parts of the digestive system different colors to be able to identify different organs.



Picture from: Mountainstar.Kramesonline.com

1.The Digestive System

So digestion begins with your mouth and ends with your anus. Your body breaks the food down,

absorbs what it can use, stores what it needs, and releases what it cannot through our urine or stool.

A healthy diet is important to a healthy colon. Can you think of some things that happen to your stomach that might tell you that your colon is not working properly or is not healthy? Think about when you eat too much in a short amount of time?

- Bloating is swelling or increase of the stomach. This is not weight gain, but caused by gas or air.
- Gas – seen as burping or farting.
- Pain - sometimes your stomach can hurt and you feel like you would be better if you could just burp or fart to get some of the air or gas out of your stomach.

Go over the Diseases of the Digestive System wall chart.

As you get older there are more things about your body that you need to take care of to stay healthy.

2. Colon Cancer : symptoms and diagnosis

Colon cancer is cancer of the colon. ***Show the colon on the wall chart.*** It is the 3rd most common form of cancer diagnosed in men and women in the US. There are some things that increase your risk for getting colon cancer. Some of them are:

- Age 50 and older
- Race – African Americans are at greater risk
- Diet – high fat, low fiber diets ***Give examples of the types of food that are high fat, low fiber.***
- No physical activity
- Smoking
- Alcohol
- Family history

Pass out the handout on Low Fat High Fiber Foods. Discuss the role nutrition plays in keeping our bodies healthy and that healthy foods fuel our bodies while unhealthy foods weigh us down and make us sick.

Pass out the Bingo Cards and blotters so each participant has a card. The trainer can call the Bingo Game. Trainers should make sure they review the Bingo game rules and identify for the group what constitutes a Bingo. It will also drive

the learning home if participants identify on their cards which foods are high fiber and which are low fat.

Session 3

Colon Cancer

Supplies Needed:

- Sign In Sheet
- Rules
- Class Schedule
- Digestive System Wall Chart
- Crayons
- Diseases of the Digestive System Poster
- Colonoscopy vs Sigmoidoscopy Poster
- Fecal Occult Blood Test
- Polyp Models
- Participant Folders
  - Digestive System Coloring Sheet
  - Colon Cancer Handout

Review what has been learned so far…

Where is the colon located in the body?
What system does it belong to?
What is its function?
What increases your risk of getting colon cancer?

1. Signs of Colon Cancer

Many people display no symptoms of colon cancer. However, some people may have:

- Change in bowl movements
- Blood in the stool
- Stomach pains
- Loss of appetite
- Weight loss
- Constant tiredness
- Nausea or vomiting

There are some things you can do to reduce your risk of cancer. You can:

- Exercise
- Stop smoking
- Lose weight
- Take folic acid
- Take aspirin
- Get more calcium in your diet
- Get more vitamin D in your diet
- GET SCREENED!

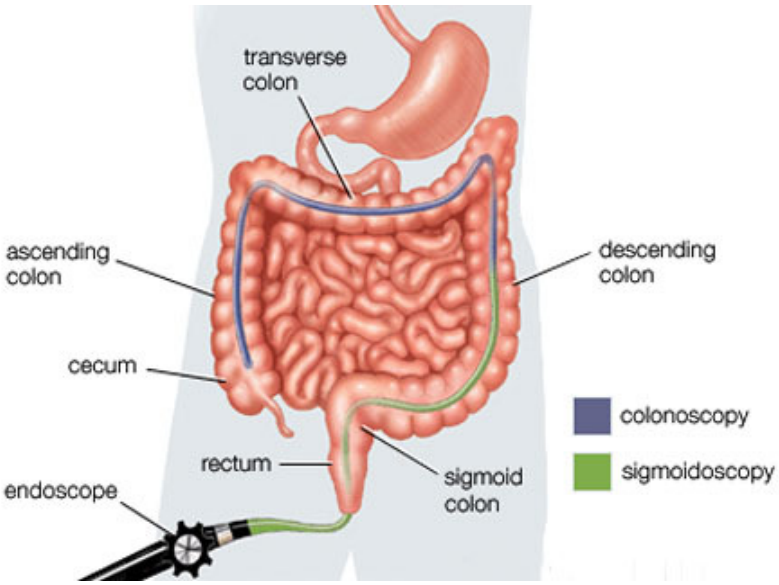
2. Screening for Colon Cancer

   - FBOT – fecal blood occult test – looks for blood in your stool which is a sign of cancer, but is less likely to find polyps.

   Look at the FOBT in the Trainer's Kit. This includes specific instructions on use. An individual should urinate and flush the toilet.

Then have a bowel movement and do not flush the toilet. Take a test tissue out of the FOBT package and float it on the toilet water. Look for a blue green color on the test tissue and record the results on the Test Result Card. Flush the toilet. Open the Positive Control Package and sprinkle the contents into the toilet while it is filling up in the bowl. Wait one minute and drop in another test tissue in the toilet bowl. Within 2 minutes, a blue green cross should appear on the tissue. Wash your hands and record the results on the Test Result Card. Any trace of blue green color in the test area indicates that blood may be in your stool. If this occurs contact your doctor.

- Sigmoidoscopy – The doctor inserts a camera tube up your anus and into your descending colon looking for polys and cancer. This procedure does not look at your entire colon, and may miss signs deeper into your transverse and ascending colon.



- Colonoscopy – looks for polyps and cancer and looks at the whole colon.

Colonoscopies can show irritated and swollen tissue, ulcers and polyps or extra pieces of tissue that grow on the lining of the intestines. Polyps are small growths that over time can become cancer. ***Look at model of polyps.***

During a colonoscopy a doctor will run a tiny camera through your rectum into your colon to look for polyps or cancer. ***Use the colonoscopy vs sigmoidoscopy poster to show a visual of this.***

Most of the time, patients are asleep during the actual colon screening. If a doctor asks you to get a colonoscopy, the preparation process is more uncomfortable than the screening. You have to

make sure you colon is clean so you get a good picture of your colon. This allows the doctor to see your colon and any polyps more clearly.

The cleansing process is very important!

Review the polyp models with the class. Using crayons, have them draw polyps on their Digestive System Color Sheet.

3. Health Advocacy

Even though our staff knows a lot about us, it does not mean they can know how you are feeling inside. As an adult we are all responsible for taking care of our health. Your support staff can help, but everyone needs to work with their doctor to make sure they are as health as possible. Part of working with you doctor is being strong enough to talk to them about uncomfortable topics.

Let's Practice. I need 1 volunteer.

We are going to role model or practice talking to a doctor or nurse. This is my doctor and I am going to try to talk with them about some symptoms that I am

having. I want you to pay attention and tell me what I am doing wrong.

The trainer will relate troubling symptoms to the "doctor" participant of the training. This can be problems having bowel movements, stomach pains, diarrhea, etc.. The trainer should not make direct eye contact, they should not say directly what is wrong, they should speak in a low voice that is difficult to hear, generally display manner that show signs of being uncomfortable. If you have witnessed signs in person from folks you serve, use those.

Ok, now let's talk about how that went. What did I do wrong? ***Make sure the participants hit on everything you purposefully portrayed wrong.*** Ok now is there anyone who wants to come show the group how I should have talked to the doctor?

If there are folks who feel uncomfortable doing this in a group setting, ask their case manager or direct care staff to practice with them. Ask the group to practice in the mirror at home before the next class.

Class 4

Colon Cancer Screening & Preparation – Getting Ready!

Supplies Needed:

- Sign In Sheet
- Rules
- Class Schedule
- Digestive System Wall Chart
- Colonoscopy vs Sigmoidoscopy Poster
- Colonoscopy Prep Kit
- Hospital Gown
- Balloons
- Participants Folders
- Colon Cancer Jeopardy Game
- Training Certificates
- Awareness Bracelets

Review the colon information from Class 2 using the digestive system wall chart.

1. Colorectal Cancer Screenings

Ok so your doctor says you have to have a colonoscopy. As adults we sometimes have to do things we find unpleasant or do not want to do. However, if we are going to take care of our bodies we have need to work with our doctors and have all

of our preventive screenings. People do not usually enjoy getting ready for a colonoscopy, but all adults should have this screening when they turn 50 and again every 10 years after. Talk to your doctor about this screening and follow their recommendations.

The doctor will give you an instruction sheet to help you get ready for your colonoscopy.

Here are some pretty typical instructions.

A. Follow a special diet the day before the exam. Usually this is a liquid diet. Water, tea, coffee without cream or milk, broth, and carbonated drinks. Stay away from red liquids.

On flip chart paper, make a list of possible liquids that could be used during the special diet day.

B. Take a laxative. Your doctor might suggest you take a laxative in either pill or liquid form. A laxative will clean out your colon by making you go to the bathroom until you have nothing left in your colon. Diarrhea is common. Most people find drinking the laxative to be difficult. It usually does not taste good. Some people suggest drinking 64 oz of Gatorade to help the taste.

Some suggest drinking a glass of the laxative and then drink a glass of something else (broth, carbonated drinks, tea) to get the bad taste out of your mouth. It is a good idea to create a prep kit of a variety of liquid options.

Review the prep kit. Take out each item pass them around and discuss what each is for or what could be changed to accommodate individuals in the group. The entertainment items can easily be individualized. Discuss why you would want or need entertainment items.

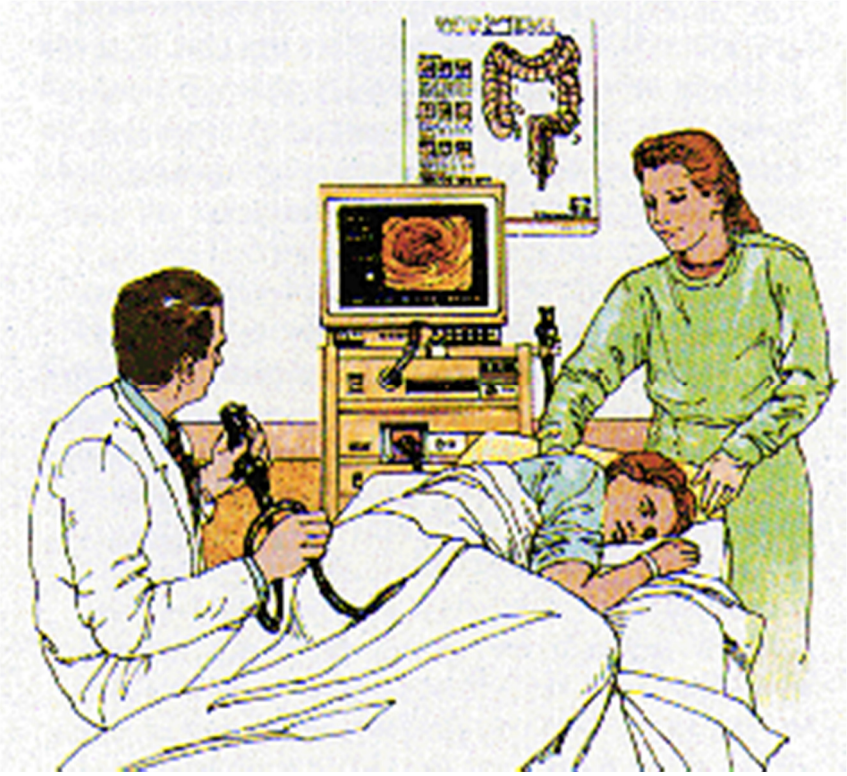
C. Use an enema. Sometimes your doctor will have you use an over the counter enema kit the night before and the morning of the colonoscopy. Follow your doctor's instructions; he/she may not have you use the enema.

D. Adjust your medications. Your doctor should know what medicines you are taking at least a week before the exam. They may have you adjust your dosages or have you stop some meds until after the exam. Do not change your medication dosage unless your doctor tells you to do so.

During the exam, you will wear a hospital gown with nothing on underneath.

Look at the hospital gown in the training kit. Pass it around so the group can see how it works or get a participant to model it for the group. The idea is for them to become comfortable with the gown.

Usually the doctor puts you to sleep during the exam. For the exam, you will lay down on the exam table on your side with your knees drawn to your chest.



Picture from: centerforadvancedgi.net

The doctor will put a colonoscopy (a small tube with a camera) up your rectum and through your colon.

They are looking for polyps. ***Use the Polyp Models in this discussion.*** During this exam, they may inflate the colon causing stomach cramps or the feeling like you need to go to the bathroom.

Blow up long skinny balloons to simulate the air in the abdomen. Discuss with the group how the doctor will use air to blow up the colon (like the balloon) so the camera can more easily slide up the colon to look for polyps or other signs that there is something wrong in the colon.

This procedure usually takes only about 20 minutes to an hour.

After the test, it can take up to an hour to wake up. Someone will need to drive you home. You may feel like you need to pass gas after the exam. Walking may help this feeling. Your first bowel movement after the test may have a small amount of blood in it. This is to be expected. If you continue to pass blood or blood clots, have stomach pains longer than the day of the exam, or have a fever of 100 degrees or higher call your doctor.

Once the screening is over your doctor will tell you if they found anything that they are concerned about.

If not, the doctor will tell you that your screening was clear and send the results to your regular doctor.

If they find one or more polyps, tumor, or anything else, they will try to remove it during the procedure. They will send it off to the lab to have it typed. Depending on the type of polyp or tumor and whether it already contains cancer cells, results could include:

- Routine follow up with a doctor
- Follow up colonoscopy
- Colectomy or removal of part or the entire colon.

Typically the doctor will let you know the day of your colonoscopy whether they are concerned about your screening results and will share their thoughts on follow up. Since you will still be groggy from the procedure, it is best to have a family member, close friend, or staff member to be with you during this conversation.

Even though the preparation for this screening can be unpleasant, the screening can be uncomfortable, and the possible results could be scary - we must take care of our bodies. Preventive screenings are the best way to do that.

So we have learned a lot the last 4 classes. Let's review everything with a Health Jeopardy game.

Split the class into two groups and play the game by the rules included. This can also be done in conjunction with a graduation. At graduation, each participant will get a certificate of training a blue ribbon sticker, water bottle, and a colon cancer awareness bracelet.