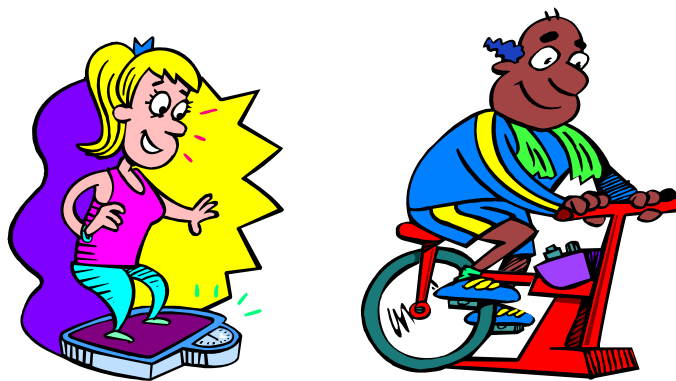


Staying Healthy What You Can Do!



A Health Education Program for Teens and Adults with Prader-Willi Syndrome

Lesson Plans and Ideas

Created by Barb Dorn, RN, BSN
PWSA of WI, Inc
2007

Introduction

I believe that most people with Prader-Willi syndrome (PWS) are capable of learning how to care for their health and their bodies. Some may learn very quickly; others will not. We must create opportunities for them to learn. Learning can take place in many different environments – in school, at home and in the community. It can be done by teachers, trainers, parents and/or care givers. There are many different opportunities to teach, reinforce and be role models to the teen and adult with this disability.

The purpose of this health education program is to empower individuals with PWS in learning about their bodies, how it works and what they can do to help themselves stay healthy.

This program has been developed using an approach where the material presented is done during two class periods of 1 hour each. Thirty minutes of each class time is devoted to the presentation and discussion of a variety of health topics. A power point presentation has also been created to accompany the class. The use of additional props and supplies are encouraged.

The final 30 minutes of each class has been designed to include “Good Health” BINGO. This game utilizes pictures and discussion of topics that reinforce concepts taught during class time. It also provides a social opportunity and a time to have fun. Flash cards have been created to help the participants by providing a visual aid for the Bingo spaces. Also, as part of the Bingo game, it is suggested to purchase or obtain small health-related items that you can distribute as prizes. People with PWS love to walk away from an activity with something. Some ideas for prizes include: small sample-size lotions (ask friends and family members to save these when they stay in a hotel), toothbrushes, sample-size toothpaste, sunglasses, small bottles of water, and hats/visors.

You may want to modify these lesson plans. Be creative. Some may want to present and discuss one or two health topics at one time; followed by the Good Health Bingo game. Some may want to make this a weekly event; featuring different topics at every class. My intention is to give parents, caregivers and anyone who may assume the role in providing health education to these individuals – ideas, approaches and tools to make this process easier and more meaningful. Ask the participants to share what they are doing to stay healthy.

I hope you will feel motivated to help persons with PWS gain a better understanding of how their body works and what they can do to learn and improve their health practices.

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| <p>PWSA of WI, Inc gratefully acknowledges “Colleen’s Angels” for their generous contribution to this project in order that we may continue our health education and health awareness efforts.</p> |
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LESSON PLANS – AN OVERVIEW

Time Allocation: 2- 1 Hour Classes (30 min instruction, 30 min. activity)

Outcomes:

At the completion of class 1, persons with PWS will be able to share:

- PWS is a problem on their 15th chromosome.
- No one did anything to cause PWS.
- He/she may not have a fever when they are ill.
- He/she should TELL SOMEONE if/when;
 - He/she sneaks' food and over eats.
 - He/she vomits.
 - He/she falls and bumps him/herself.
- He/she can keep their hands busy or a sore covered with a bandage or other items (socks, gloves ...) to help them try not to pick at sores.

At the completion of class 2, persons with PWS will be able to share:

- It is important to wear sunscreen, sunglasses and/or a hat in the sun.
- It is important to brush teeth 2 times a day.
- He/she should TELL SOMEONE if/when:
 - He/she falls and hurts a bone.
- One thing that he/she can do when they have a concern or feelings they need to share.
- It is important not to drink a lot of fluid at one time.
- Some people with PWS have sleep apnea and need a machine to help them breathe better at night.

CLASS 1

TOPICS:

1. What is Prader-Willi syndrome?
2. What Caused Prader-Willi syndrome?
3. Temperature Control and Fever
4. Stomach Illness
5. Vomiting
6. Pain
7. Skin Picking

CLASS SUPPLIES:

- Thermometers / alcohol pads
- Deck of cards, magazine, beads, hand held games and other items that can provide a visual idea of things they can do/use to provide diversion during times when they want to pick at their skin

ACTIVITY:

- Good Health Bingo

BINGO GIVE AWAYS

- Lotion

CLASS 2

TOPICS:

1. Sun and medication sensitivity
2. Dental care
3. Osteoporosis – bone care
4. Controlling Feelings and behavior
5. Preventing Water Intoxication
6. Breathing and lung problems

CLASS SUPPLIES:

- Sunscreen
- Sun glasses
- Hat
- Toothbrushes, toothpaste, dental floss
- Milk /yogurt container
- Large container of water and small bottle of water

ACTIVITY:

- Good Health BINGO

CLASS PRIZES - GIVE AWAYS

- Toothbrushes /sample size toothpaste

BROCHURES:

- Health Information for the Person with PWS
- Medical Alert for Parents and Caregivers
- Medical booklet for Health Care Professionals

CLASS 1

TOPICS:

1. What is Prader-Willi syndrome?
2. What Caused Prader-Willi syndrome?
3. Temperature Control and Fever
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CLASS SUPPLIES:

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ACTIVITY:

- Good Health Bingo

BINGO PRIZE - GIVE AWAYS

- Lotion

LESSON PLAN:

- I. Welcome
 - We are going to talk about your body, your health and what you can do to help to stay healthy.
- II. What is Prader-Willi syndrome?
 - A condition a person is born with in which there are problems and/or challenges that require extra help or support throughout his/her life.
 - It affects health, learning, behavior and the ability to control ones' appetite.
 - It is caused by a problem on the 15th chromosome
 - What is a chromosome?
 1. Very, very tiny "messenger" cells that tell our body what to do and how to work.
 2. We get chromosomes from our parents.
 3. Chromosomes are so small that doctors and scientists need special microscopes to see them.
 4. Emphasize how small they are.
 - An area of the brain (the hypothalamus) doesn't work right. This part of the brain
 1. Controls your appetite
 2. Affects your feelings
 3. Controls your body temperature
 4. Produces hormones that help with growth and reproductive ability.
 - Because it doesn't work right ... it makes you:
 1. Feel hungry all of the time.
 2. Be sensitive to your feelings.
 3. Be shorter and have bones that break easily.
 4. Your body not work the way other peoples' body works and you may have special health concerns.
 5. Not experience some of the same changes sexually as others your age –
 - Smaller breast development
 - Not as much beard growth

- Small penis
- May not have a monthly menstrual period.
- Most are not able to have children.

III. How Did This Happen?

- We don't know why a person's body does this but we do know that your mom and dad did not do anything that they knew would cause this to happen.
- What we DO know is that:
 1. YOU and YOUR PARENTS did not do anything to cause this.
 2. IT IS NO ONES' FAULT!

IV. Things About PWS that Affect Your Health

- Your temperature control center may not work correctly.
 1. You may not run a fever when you are sick.
 2. You may feel cold – even when it is hot.
 3. You may have your temperature go up very easily – especially on hot days.
- **ACTIVITY: WHAT IS YOUR TEMPERATURE?**
 1. What is a person's normal body temperature?
 - a. Around 98.6 degrees

What Can You Do?

- TELL SOMEONE if you are not feeling well. They can help you figure out if you are very sick.
- When it is warm outside, wear clothes that will help your body to stay a little cool.
- Don't exercise outside or stay outside for a long time.
- When it is very cold outside, wear clothes that will help your body stay warm – but not too warm. Don't exercise outside or stay outside for a long time.

- **Overeating Can Cause Stomach Illness.**
 1. People with PWS have a problem in their brain that does not let them know when they are full. This causes people with PWS to over eat.
 2. Some people with PWS have gotten very sick and a few people have died when they have eaten too much and have not told anyone.
 3. Your stomach only has so much room. If you eat too much – it stretches it to the point where it swells up and sometimes it can get a hole in it. People get very sick when this happens.
 4. Most people with PWS do not vomit.
 5. Vomiting helps us get rid of bad germs. It can also tell us when we are sick.
 6. When someone with PWS vomits – we want to make sure you do not have a serious problem.

What Can You Do?

- TELL SOMEONE if you sneak food and overeat. He/she can make sure you are ok and help you.
 - They will not be mad at you.
- TELL SOMEONE if you vomit. They will want to make sure you are ok.

- **Things Don't Hurt You Very Much.**
 1. Pain helps us know when we have a problem. It can be a good thing.
 2. Most people with PWS do not feel pain the way others do.

What Can You Do?

- TELL SOMEONE if you fall down or bump yourself. Let someone make sure it is ok.
- Rest an area that may be injured. You may need to elevate it and put ice on it to help it get better faster.

- Picking at Your Skin

1. Many people with PWS pick at their skin. We do not know exactly why people do this but it can become a habit that is hard to stop.
2. It is important for you to try to help by keeping your hands busy.
3. **Can anyone tell me other things they do to help themselves not to pick?

What Can You Do?

- Keep your hands busy – put lotion on your hands, shuffle cards, play a game, color, do a puzzle, work on beads or any other activity that helps you not to pick.
- Don't spend a lot of time alone. It can help to be around other people.
- Help others to help you. (Don't get mad when someone tries to give you suggestions. Don't hide)

Props: Lotion, deck of cards, magazine, word search, hand held game

V. Summary

- (Ask as true or false questions – all are true!)
 1. PWS is a problem on the 15th chromosome.
 2. No one did anything to cause PWS.
 3. A person with PWS may not have a fever when they are ill.
 4. A person with PWS should TELL SOMEONE if/when;
 - a. He/she sneaks' food and over eats.
 - b. He/she vomits.
 - c. He/she falls and bumps him/herself.
 5. Keeping your hands busy may help a person if they feel they need to pick at their skin.

CLASS 2

OUTCOMES:

After completion of class 2, persons with PWS will be able to share:

- It is important to wear sunscreen and to wear a hat/sun glasses to protect them from sun burn.
- They should brush their teeth at least 2 times a day.
- They may have softer bones; exercise helps their bones to be stronger.
- They may have trouble controlling their feelings but they can do things to help:
 - Use words to share what is bothering them.
 - Go somewhere where they can calm themselves.
- They should not drink a lot of fluids at one time or they could get very sick.
- They may get lung infections easier so when they get a cold, they should
 - Get up and keep moving – even if they do not feel well.
 - Talk to their doctor about getting a flu shot every year.

TOPICS:

- A. Sun Sensitivity
- B. Teeth and Dental Care
- C. Bones that May Break Easily
- D. Controlling Your Feelings
- E. Drinking too Much Fluids Can Make You Sick
- F. Breathing Problems – Preventing Lung Infections

CLASS SUPPLIES:

- Sunscreen
- Sun glasses
- Hat
- Toothbrushes, toothpaste, dental floss
- Milk /yogurt container
- Large container of water and small bottle of water

ACTIVITY:

- Good Health Bingo

BINGO GIVE AWAY

- Toothbrushes

BROCHURES:

- Health Information for the Person with PWS
- Medical Alert for Parents and Caregivers
- Medical booklet for Health Care Professionals

LESSON PLAN:

- I. Welcome Back
 - We are going to talk about your body, your health and what you can do to help yourself stay healthy.
- II. More things You Need to Know about PWS and Your Health
 - Sun Sensitivity
 1. Many people with PWS may sunburn easily.
 2. Some people take medicines that can also make them sun burn easily.

What Can You Do?

- Protect your skin and eyes.
- Apply sunscreen when you go outside.
- Wear a hat – a hat with a rim or a “bucket hat”. This helps to protect your head, ears and eyes.
- Wear sunglasses to help protect your eyes.

Props: Sunscreen, sunglasses, bucket hat

- Tooth and Dental Care
 1. Many people with PWS have thick saliva in their mouth and can have more problems with their teeth.
 2. It is very important to take care of your teeth.

What Can You Do?

- Make sure to brush your teeth very good at least 2 times every day.
- Floss your teeth every day. If you need help with this – ask.
- See a dentist 2-3 times a year or as often as the dentist tell you to.
- Drink 6-8 glasses of water or sugar-free fluid every day.
- Avoid drinking a lot of diet soda. This can damage your teeth.

Props: Toothbrushes, toothpaste, water, dental floss

- Bone Care and Safety
 1. Many people with PWS have soft bones that can break easily.
 2. You may fall or slip and not realize that they hurt themselves.
 3. Things that help keep bones strong.
 - a. Hormones
 - b. Calcium and Vitamin D (Many milk products contain calcium and Vitamin D – cheese, yogurt, milk). Nowadays, there are a lot of foods that have extra calcium added to them.
 - c. Exercise

What Can You Do?

- TELL SOMONE if you fall or hurt a bone.
- Eat foods that help you get calcium and Vitamin D – milk, cheese, yogurt.
- Spend 15 minutes a day in the sun (best source of Vitamin D).
- Exercise every day.

Props: Empty milk container, empty yogurt container.

- Controlling Your Feelings
 1. Many people with PWS may have trouble controlling their feelings.
 2. Sometimes they may become upset or angry very fast.
 3. Many people take medicines to help them control their feelings.
 4. People care about you and want you to be safe.
 5. We want others to respect you and not be afraid of you. (That is why there may be times when it is better to stay at home and not go out when your feelings are more sensitive).

What Can You Do?

- Tell people how you feel – use words. Help others understand.
- Find a way to be safe when you are upset – go to your room; rest on your bed.
- Try doing something you enjoy. Listen to music, do a puzzle. (It may help you feel better and make you happy again)

- Fluids Are Good for You But Drinking too Much Fluids Can Make You Sick
 1. Water is very good for your body. It helps many parts of our body work well.
 2. Drinking too much water or any fluid at one time can make you sick.
 3. It is best to drink fluids in smaller amounts and take a break.

What Can You Do?

- Continue to drink fluids to keep your body healthy.
- Do not drink more than a medium glass at one time.
- When you drink them – space them out.

Props: Different size cups and beverage containers – ask what would be ok to drink at one time – what would not.

- Breathing Problems – Preventing Lung Infections
 1. Many people with PWS have weak muscles in their chest area.
 2. Sometimes, when they get a cold, they may get a lung infection easily.
 3. If the person with PWS is overweight, it can be hard for them to breathe.

What Can You Do?

- If you get a cold, it is important to move around, cough, and drink fluids so you do not get a bad lung infection.
- You may need to get a flu shot every year. Your doctor or nurse will help you decide if this is right for you.
- It is important to try to keep your weight under control.

- Breathing Problems – Sleep Apnea
 1. Some people with PWS also have a problem breathing properly when they sleep.
 2. Some people have a condition called sleep apnea – a condition where they stop breathing for too long while asleep.
 3. Their doctor may do special testing and have them wear a special mask and use a machine to help them so they get better rest.

What Can You Do?

- If the doctor thinks you are having problems breathing while you sleep, he/she may order a special test to check this. It is important to cooperate.
- If you need to wear a special mask and use the machine when you sleep - it can be hard at first.
- Talk to the nurse or doctor to get some tips to make this easier.

III. Summary

A. Ask true and false questions – where they are all true.

- It important to wear sunscreen and to wear a hat/sun glasses to protect your self from sun burn.
- You brush their teeth at least 2 times a day.
- People with PWS may have softer bones and exercise helps bones to be stronger.
- You may have trouble controlling your feelings but you can do things to help yourself like:
 - Using words to share what is bothering you.
 - Going somewhere where you can calm yourself.
- Water and fluids are good for you but you should not drink a lot of fluids at one time or you could get very sick.
- You may get lung infections easier so when you get a cold, you should
 - Get up and keep moving – even if you do not feel well.
 - Talk to your doctor about getting a flu shot every year.

We all want to BE healthy. In order to do this, we must do things that will help us STAY healthy. You can do these things too.