HEALTHY FUTURES

A guide for adults
with
Prader-Willi syndrome
The Healthy Futures Project is kindly sponsored by Aviva
Contents

- What is Prader-Willi syndrome?
- Healthy lifestyle - diet and exercise
- How to cope when anxious or upset
- Looking after your eyes
- Looking after your teeth
- Relationships
- Social life and hobbies
- Things my GP needs to know about PWS
- Things I can do - Activity Sheets
Welcome to your Healthy Futures Pack.

We hope that the information in this pack is helpful.

There are leaflets in your pack that cover different things that happen as part of your everyday life. The leaflets have information and ideas of things you can do.

The PWSA UK Owl Focus Group have read the leaflets too and shared some ideas that have been included. Gurveer Singh Sohanpal, a 34-year-old adult with PWS, who has lived at Heatherington House for 3 years with seven others who also have PWS, explains here how the Owl Focus Group has helped with this pack:

Hi Everyone!
At the Owl Focus Group meeting, I was asked to take part in getting together a short introduction for this pack. The Owl Focus Group, discussed some topics suggested to them by the PWSA UK Trustee Board, and decided the most important subjects for the pack were:

- How to cope with anxiety
- Relationships
- Social life and Hobbies
- Healthcare including care of the eyes and care for your teeth.

We also decided it should be put together in booklet form.

Gurveer Sohanpal

We do hope you find this pack useful.

Susan Passmore
Chief Executive
What is Prader-Willi syndrome?
What is Prader-Willi syndrome (PWS)

- PWS is rare and only affects a few people
- That means a lot of people don’t know what it is
- Your brain works differently

- Not everyone with PWS is the same
- You will notice other people with PWS can be like you and they can be different to you too
• The messages between your brain and your tummy don’t work to tell you to stop eating

• It is important to follow your diet plan and only eat food that has been agreed

• Eating too much food can make you put on weight

• Too much weight is not good for your body

• Exercise can also help to control your weight too

• Some people’s muscles don’t work so well

• This can make walking or exercising more difficult for some people

• Food takes longer to go through your body, and that might affect how often you go to the toilet

• Being sick is something most people with PWS do not do

• If you are sick, you need to tell someone straight away
• Your body may not feel like it’s hot or cold like others do

• Sometimes you need others to make sure you have the right clothes on to match the temperature inside or outside

• Some people can be more tired than others, as they don’t sleep as much and may need extra rests during the day

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Things I Don’t Understand

• Some people with PWS need extra support to understand things other people say

• It’s ok to say you don’t understand what people say to you

• It is also okay to ask others to repeat things so that you understand them
Healthy lifestyle - diet and exercise
Healthy lifestyle - diet and exercise

- Diet is all about what and how much you eat
- Because you have PWS you need to eat fewer calories than people without PWS

- Exercise is really important to burn off calories
Eating healthy

- Talk to your doctor or dietitian, they can help you with how many calories you can have every day

- If your doctor does not know about PWS, you can call PWSA UK on 01332 365676 for a leaflet to take with you

If you need to lose weight:

- Weigh yourself once a week on the same day

- Get a Weight Loss Chart

- Try to lose 0.5—1kg a month

- Take a photograph of yourself to see the difference
Eating healthy
What should I eat?

It's a good idea to get a special plate which is divided into sections:

- One small part for protein which is meat, fish, eggs and cheese
- The other small part is for carbohydrates which is pasta, potatoes and rice
- The large part is for vegetables and salad

You can also have:

- Berries—strawberries, blackberries, blueberries, blackcurrants which are lower in sugar
- Other fruits once a week
- Dried fruit, such as sultanas, once a week
- Low fat yoghurts and spreads
- Skimmed milk which is lower calorie
- Diet drinks once a week
Eating healthy
Calories and food labels

- Most food packaging says the amount of calories on it
- How much sugar is in it
- How much fat is in it

Look at labels carefully though, ‘low fat’ and ‘low sugar’ do not always mean ‘low calorie’

Food preparation

- Always have a list when you go shopping and stick to it
- Always grill, boil or bake food
- Soups are really healthy and you can make lots of different flavours
- There are many healthy, low calorie recipes on the internet for you to try
Different people prefer different healthy foods

- Write some of them below

Healthy foods I like to eat are:

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Regular exercise is good for everyone:

- It burns calories
- Improves your muscle tone
- Improves circulation
- Helps you feel awake

It is also great for taking your mind off feeling hungry

Did you know if you did the following activities for one hour you would burn off ......

- Sitting down 100kcals
- Standing 140kcals
- Housework 180kcals
- Gardening 220kcals
- Brisk walking at 4mph 330kcals
- Jogging at 6mph 750kcals
Weekly Meal Planner

Shopping List

Week of:

Weekly Food Planner

Breakfast Lunch Dinner Snacks

Sun Sat Mon Tues Wed Thurs Fri Sat
How to cope when anxious or upset
How to cope if you feel anxious or upset

- Anxiety is when you have feelings of worry or fear
- It can be about something small or something big. We all feel anxious or upset sometimes
- Tell someone you feel anxious or upset. This could be a family member, carer, teacher or a friend

- Tell the people around you that you would like some space
- Say clearly and politely “Please give me space”
- Go to your room and listen to your favourite music for 10 minutes
Picture yourself at the beach. The rays of the sun are soft and warm. You hear the sounds of the seagulls and the waves rolling gently. The waves roll in and out, in and out.

You can see the sand, and the waves, and the blue sky. You feel safe and calm. This will help you to relax.

Take a deep breath.

Close your mouth and breathe in through your nose for three seconds.

Now open your mouth and breathe out for three seconds.

Do this three times. Your parent or carer can help you practice this.

Every time you breathe out, say the word ‘relax’ quietly to yourself.
How to make a Glitter bottle—your Mum, Dad or Carer must help you
A glitter bottle can help you to feel calm

What do you need to make your glitter bottle?

- An empty plastic bottle with a lid
- Water
- Two colours of glitter
- One is for thoughts and one is for feelings

How do you make your glitter bottle?

- Put the glitter into the bottom of the empty bottle
- Carefully pour in the water
- Put the lid on the bottle, making sure it is tight
How will a glitter jar help you?

- Pick up your glitter jar and give it a good shake
- Can you see how the glitter is swirling around and around?
- This is what happens to our thoughts and feelings when we are upset or anxious
- Our thoughts and feelings can become muddled and swirl around in our heads

- Now place your glitter jar on a flat surface
- Leave it alone and watch what happens to the glitter
- Can you see how it has settled and become still at the bottom?
- This is what happens to our thoughts and feelings when we have time to relax after a mood swing
- Think about what makes your thoughts and feelings swirl around. It could be a change in your routine or loud noises

- Write some of them below

**My thoughts and feelings start to swirl when:**

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Different people find different things help them to feel calm such as stroking an animal or going for a walk

- Write some of them below

**Things I can do to help me when I’m anxious:**

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Looking after your eyes
Looking after your eyes

- You need to visit the opticians to have your eyesight checked. You normally go every 2 years.
- The optician needs to know you have PWS so they can do extra checks to keep your eyes healthy.

Things you should tell the optician:
- Do words seem fuzzy when you are reading?
- Can you see things in the distance clearly?
- Do you get headaches or feel tired after watching TV, playing games or reading?
- Some people with PWS need glasses to help them see better
- Some people have glasses for seeing things in the distance
- Some people have glasses for seeing things close up, like when reading
- Some people have glasses to help them see all the time

- There are leaflets you can take to the optician that helps them understand PWS. Your parent or carer can get the leaflets from the Prader-Willi Syndrome Association
Looking after your teeth
Looking after your teeth

Cleaning your teeth every day is really important

- Some people clean them in the morning and at night
- Some people clean them after each meal

- Healthy teeth and gums means a nice smile and less treatment at the dentist

Regular visits to the dentist are important too

- The dentist needs to know you have PWS
- They need to give your teeth extra care to help protect your teeth from decay
• The dentist needs to know about any problems with your teeth or gums

Things you should tell the dentist:
• Are any of your teeth wobbly?
• Does it hurt when eating or drinking hot or cold things?
• Do your teeth feel strange when you eat food?
• Do your gums bleed when you brush your teeth?

• The dentist needs to know that some people with PWS don’t feel much pain. You may not be feeling pain but there may be a problem with a tooth

• There are leaflets you can take to the dentist that helps them understand PWS. Your parent or carer can get the leaflets from the Prader-Willi Syndrome Association
Relationships
Relationships

- You might have lots of friends that you like spending time with
- Friends get on well together and you might go to the cinema with them or for a walk or just chat together
- If you have one special friend that you like a lot, this friend could be your girlfriend or boyfriend, or your partner
- Your partner could be someone you like to kiss and cuddle
- When you have a boyfriend or girlfriend, you say that you are ‘in a relationship’ or ‘going out with them’

There are different sorts of relationships

- A gay relationship is when men like other men and want to be in a relationship with them
- A lesbian relationship is when women want to be in a relationship with other women
- Some people like to be in a bi-sexual relationship with a man or a woman
- You don’t have to be in a relationship, and may be happy being single
• If one of your friends asks you to go out with them and you don't want to, it is ok to say no

• You can still be friends

• If a stranger asks you to go somewhere with them, you must say no, even if they seem nice or offer you presents or food

• Always tell your parent or carer if someone you don't know asks you to go with them

• You might need support from your carer or family to be in a relationship

• If your partner chooses not to be in a relationship with you any longer, you might feel upset

• If you are feeling sad, find someone to talk to like a parent or carer or another friend
Getting engaged or married

- Sometimes people who fall in love want to get engaged
- This means that your boyfriend or girlfriend asks you to marry them
- They usually give you a ring to wear
- This shows other people that you are engaged
- Getting married means that two people have a special ceremony and make promises to love each other
- You might need support to live with your partner

If you would like to find out more information about relationships you can watch the Prader Willi Syndrome Association videos called ‘Growing up with PWS’

Ask your carer or parent to watch them with you so that you can ask any questions you might have
Social life and hobbies
Social Life and Hobbies
People's social lives are all different — our social life is all about doing fun things we like, with people we like.

People get involved in different things depending on:
- What they like to do
- What they want to learn to do
- What is available in their local area
- What their friends and families do
- What activities they can afford to take part in

- If you live at home with family they can help you get involved in things you may want to do

- Depending where you live in the country you will have different activities you can take part in
• If you live in Residential Care or Supported Living your key worker can help you get involved in activities

• Talk to them about what you’d like to do and they can see if they can help you do it

• If you see something advertised you’d like to do — talk to your key worker to see if you can do it

• If you’re asked to take part in an activity and you don’t want to it’s ok to say “No thank you, not this time”

• It’s also ok to say ‘Yes please’ next time they ask you — changing your mind is ok
- Some activities only happen at certain times on certain days of the week

<table>
<thead>
<tr>
<th>MONDAY</th>
<th>TUESDAY</th>
<th>WEDNESDAY</th>
<th>THURSDAY</th>
<th>FRIDAY</th>
<th>SATURDAY</th>
<th>SUNDAY</th>
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</thead>
<tbody>
<tr>
<td>Word Games</td>
<td>Copehame Church</td>
<td>Active Agenda</td>
<td>Interact</td>
<td>Mike Sidaway</td>
<td>Ten Pin Bowling</td>
<td>Cadham Methodist Church</td>
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- Most activities will need some planning to be done so you can take part

Planning might be
- Having the right person available to go with you
- Ensuring you can get there - that might be by car, bus, train or walking
- Making sure you have the right clothing or footwear
- Preparing a packed lunch for you to take with you
- Reviewing the menu and agreeing what food/drink you are going to have
Sometimes planned activities can not happen, this could be because

- Someone is sick and can’t come with you
- The activity is cancelled
- The transport isn’t available to take you

If this happens stay calm, take some deep breaths and tell yourself it’s ok — let people explain what the problem is and talk about what you can do instead.
Ideas of hobbies you might like to do

Arts and Crafts
Drama
Music and Dancing
Zumba
Gardening
Pamper sessions
Shopping
Cinema
Theatre
Discos
Swimming
Horse riding
Bowling
Snooker/Pool
Work placements
Walking
Gym
Computer games
Cycling
Karaoke
Things my GP needs to know about Prader-Willi syndrome
Sometimes I will need to see a GP or doctor.
I need to tell the doctor important things about Prader-Willi syndrome.
The doctor needs to know that:

- Some people with PWS can’t control their body temperature.
- People with PWS can have a lower temperature than other people.
- My temperature is .......... if my temperature is over ...... I may be poorly.

The doctor needs to know that:

- Some people with PWS don’t feel much pain.
- This means that I could have an illness or injury without knowing about it.
- It is very unusual for people with PWS to be sick.
- If I am sick, I should tell someone straight away so that I can see a doctor.
Like most people with PWS, I have low muscle tone

- It takes people with PWS longer to digest food and sometimes we can get problems with constipation or diarrhoea
- I also get tired easily because of my low muscle tone
- It is very important for me to eat a low calorie diet so that I don’t put on too much weight

Lots of people with Prader-Willi syndrome feel hungry all the time

- This is because we don’t get a message to our brains to tell us that we are full
- It is very important for me to eat a low calorie diet so that I don’t put on too much weight
There are some other things that it would be useful for my doctor to know about Prader-Willi syndrome

- The Prader-Willi Syndrome Association has a leaflet which explains lots of things about the syndrome
- It is called ‘Information for GPs’
- My parent or carer can get a copy to give to my doctor

Going to the Accident and Emergency unit at the hospital

- The nurse will call me when it is my turn
- The nurse will need to ask me some questions
- If I can’t answer the question, the nurse can ask my parent or carer
There are things that can make people with PWS poorly. It is important for the doctor to know about these things:

- It takes longer for people with PWS to digest their food.
- That means that food moves slowly through our stomach and intestines.
- Sometimes this can make people with PWS poorly.
- Some people with PWS pick at their skin and this can cause an infection which needs to be treated by a doctor.

Things I can do to stay healthy:

**Take regular exercise**
- Go for a walk
- Go to the swimming pool
- Dance to my favourite music

**Eat healthy foods**
- Have smaller servings of fatty foods
- Eat plenty of vegetables
There are some other things that it would be useful for the doctors and nurses to know about Prader-Willi syndrome

- The Prader-Willi Syndrome Association have a leaflet which explains lots of things about the syndrome

- The leaflet is called ‘Information for Emergency Department and other hospital staff’

- My parent or carer can get a copy to give to the doctor at the hospital
Things I can do - Activity Sheets

ANIMALS

ANTS BIRD CAT COW DUCK ELEPHANT FISH GOAT HIPPO HOG HUMAN LION LIONET CAT TIGER

ANIMALS

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ANIMALS

ANTS BIRD CAT COW DUCK ELEPHANT FISH GOAT HIPPO HOG HUMAN LION LIONET CAT TIGER
Activity Sheets
Activity Sheets

Weather

blizzard  blue sky  cloudy  cold  cool  dew  downpour  dry  foggy  freezing  frost  grey sky  hail  hot  hurricane  icy  lightning  lightning  rainy  rainy  storm  snowy  sizzling  sizzling  thunder  tornado  warm  wet  windy
Countries of the World

T L A A Q D A G D D V A B N I
M K K A I D J N I C E L A N D
T A O R N S A K Y N R T L V
J W U A A L S A A E E A Y Q R
D A G R L M L U L K Z T B Q H
N U P O I B N I R R U A Y V U
A P H A A T B E T U E Q F N W
L E X N N Y I U D T L Z R M K
G C I I A G R U P M A C A K V
N A A C R L F K S T L D N E D
E P O E A D N A L O P M C N X
S Y E M E N Z A M B I A E Y Y
D C F W A L A P E N Z R Y A V
E X T N V N Y D R X P I V Q X
X M U I G L E B A V T M Y W O

ALBANIA    BELGIUM    CANADA
DENMARK    ENGLAND    FRANCE
GREECE    HOLLAND    ICELAND
JAPAN    KENYA    LIBYA
MAURITIUS    NEPAL    OMAN
POLAND    QATAR    RUSSIA
SPAIN    TURKEY    UGANDA
VENEZUELA    YEMEN    ZAMBIA
Activity Sheets

Opposites

Across
2. What is the opposite of bad?
5. What is the opposite of far?
6. What is the opposite of sad?
7. What is the opposite of hard?
8. What is the opposite of cold?
10. What is the opposite of low?
11. What is the opposite of West?

Down
1. What is the opposite of white?
3. Happy is the ______ of sad.
4. What is the opposite of wet?
5. What is the opposite of South?
6. What is the opposite of sick?
9. What is the opposite of thick?

www.boggiesworldasl.com
These websites may have more activities for you to do

www.thewordsearch.com

www.justcolor.net

www.supercoloring.com