

What is Prader Willi Syndrome?



PWS Awareness

What is Prader Willi Syndrome?

Prader Willi Syndrome or PWS
is really rare.

There aren't many people in
Ireland who have PWS.. around
120 people.

Only around 5 babies a year are
born with PWS in Ireland.



A syndrome means that something
is different or special about you

Not many people have PWS,
so not many people know much about it



PWS has lots of symptoms but it's important to remember that everyone with PWS is unique.





Everybody is made
up of DNA. It makes
us who we are.

DNA is a bit like a lego instruction book.
It has all the information in it to make a person

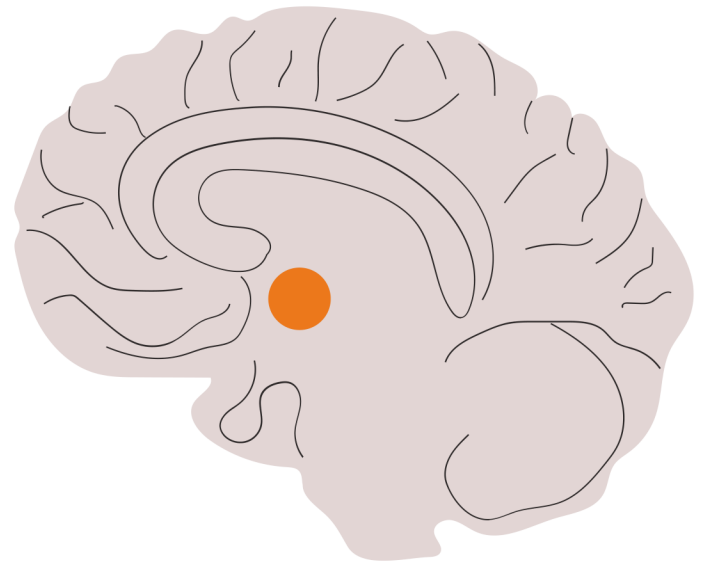


DNA gives us our
hair colour and our
eye colour.

DNA tells us what we'll be great at!
Things like sport, music and drawing!
DNA makes us all unique!

Your brain is the boss of your body,
telling it what to do.

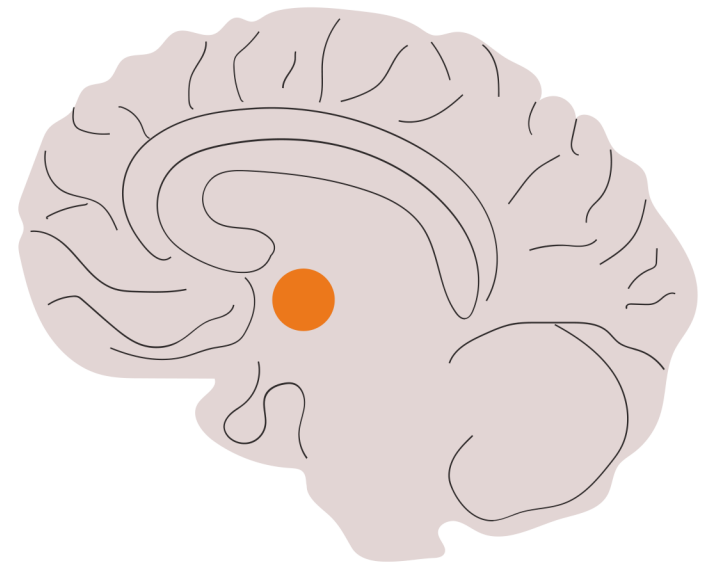
The hypothalamus is a tiny but
super important part of your brain,
like a manager in the brain's office.



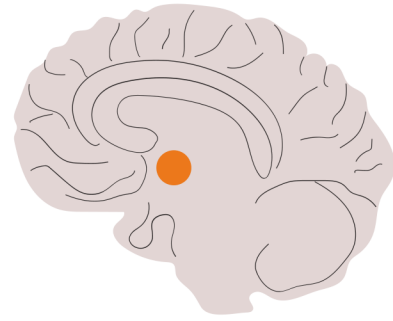
DNA has special instructions on how to make the hypothalamus and how it should work. It tells your body to build the hypothalamus and what jobs it needs to do.

Once the hypothalamus is built, it follows the instructions from the DNA to help your body know when to eat, drink, sleep, and stay warm or cool.

This part of the brain
has a fault in PWS



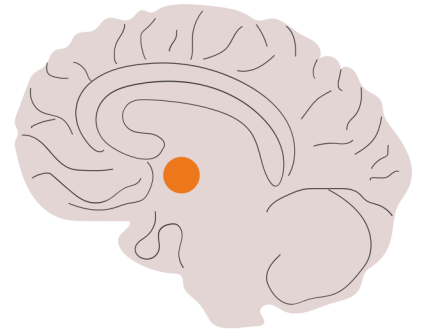
The hypothalamus's job is to keep everything in balance.



It tells you when you are thirsty.
It tells you when to sleep.

It is like a control center that helps your body adapt to different situations and changes, keeping everything running smoothly.

Here's what the hypothalamus does:



Controls Hunger and Thirst: The hypothalamus tells you when you're hungry or thirsty and when you're full. It's like your body's food and water manager.



What does this mean for a person with PWS:

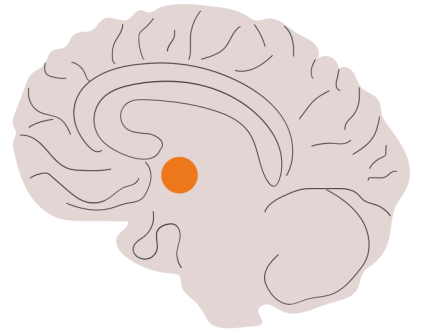
People with PWS often feel hungry all the time, even after they've just eaten. It's like their brain forgets to tell them they're full.

It's like your tummy is always asking for more food, even when it doesn't really need it. This is called hyperphagia (uncontrollable hunger)

People with hyperphagia need help to manage their eating because their bodies don't know when to stop on their own.



Here's what the hypothalamus does:



Managing Stress: When something stressful happens, the hypothalamus helps your body react by releasing hormones that prepare you to deal with the situation, like giving you more energy or making you more alert.



What does this mean for a person with PWS:

People with PWS often feel more comfortable and safe when things stay the same. Changes can make them feel worried or upset because they like knowing what to expect.

Having a routine helps them feel like they have control over their day. When something changes, it can feel like they're losing that control, which can be scary or frustrating.



Here's what the hypothalamus does:



Regulates Body Temperature:

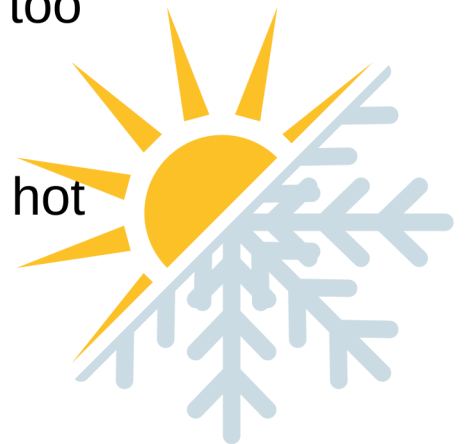
It makes sure your body stays at the right temperature, like a thermostat in your house that keeps you warm in winter and cool in summer.



What does this mean for a person with PWS:

Sometimes people with PWS need to be reminded when it is too hot or too cold.

They might need to be reminded to take off their jumper on a hot day or put on a jumper on a cold day



Here's what the hypothalamus does:



Manages Sleep: The hypothalamus helps you feel sleepy at night and awake during the day, working like an alarm clock for your body.



What does this mean for a person with PWS?

They might feel very sleepy during the day and have trouble sleeping well at night.



Here's what the hypothalamus does:

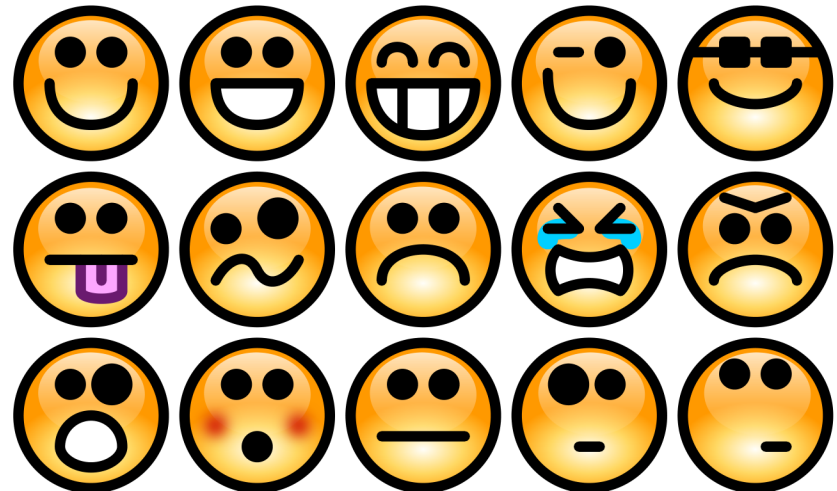


Handles Emotions: It helps control your feelings and reactions, like when you're happy, sad, or angry.



What does this mean for a person with PWS?

Sometimes, they might have trouble controlling their feelings and might get angry or upset more easily.



Here's what the hypothalamus does:



Directs Growth: It helps your body grow by controlling certain hormones, which are like special messages sent around your body.



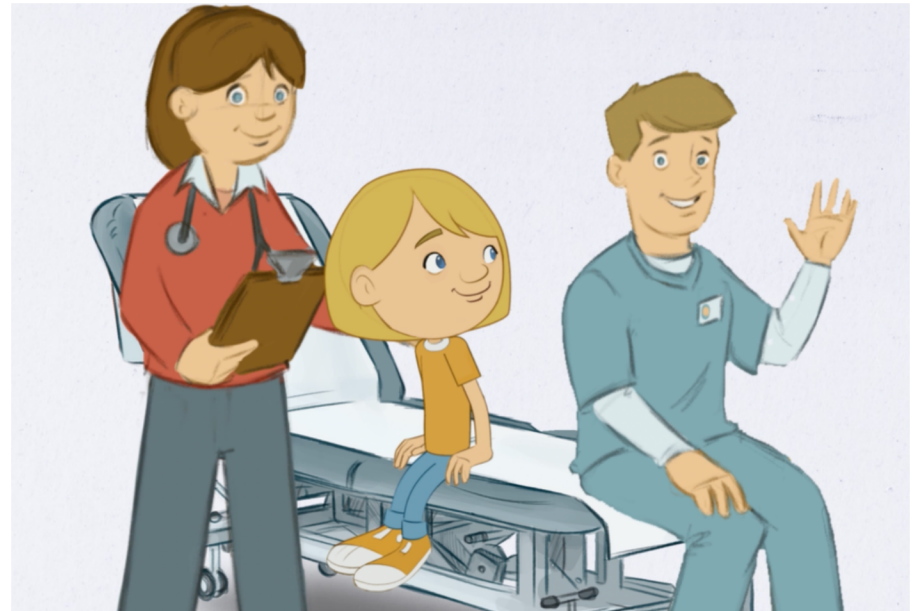
What does this mean for a person with PWS?

Most children with PWS have an injection of growth hormone every night before they go to sleep.

It helps their muscles to get stronger and helps growth.



PWS means going to **hospital** a couple of times every year to see many doctors for blood tests, xrays and check ups.



PWS means having a special diet

Children with PWS have a special diet that might look different to yours.

They follow a special food plan to keep them healthy.

This means they can't have some of the food you can- like sweets, chocolate and crisps.



At Easter, Christmas and Halloween children with PWS get toys instead of lots of chocolate or sweets.

At their birthday, they will get a special cake thats good for their tummy.

On special days in school, their parents will send in something special for them to eat when their friends get treats.



PWS means staying active

Having PWS means needing to do lots of exercise, like walking, cycling, horse riding, swimming, basketball and GAA.

Exercise is like a fun and powerful way to help kids with PWS stay strong, healthy, and happy!



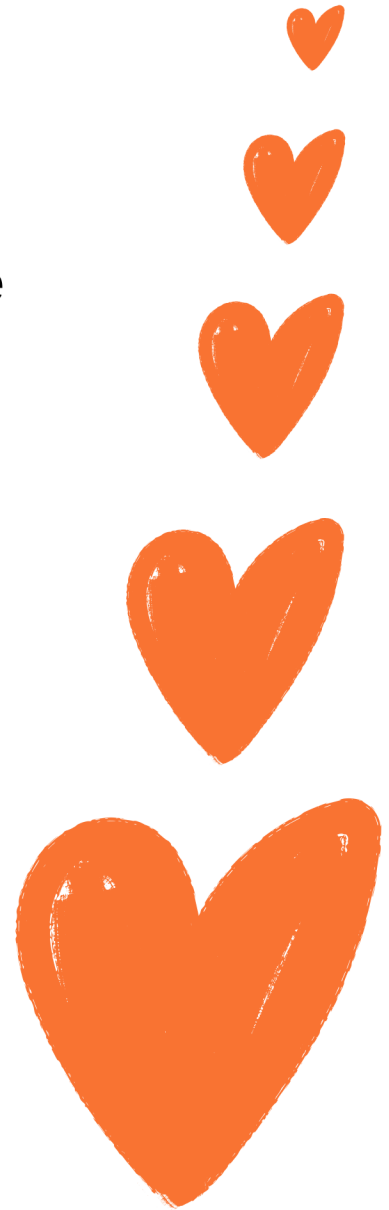
If you know a person with PWS...

Be Patient: Sometimes, your friend might need a little extra time to do things or understand something.

Include Them: Invite your friend to play with you and your other friends. They might have different interests, but they'll love being included and having fun with everyone!

Be Understanding: Sometimes, your friend might feel upset or frustrated because of PWS. Be kind.

Be Careful with Food: It's kind not to eat in front of your friend with Prader-Willi Syndrome if they're not eating.




If you know a person with PWS...

Children with Prader-Willi Syndrome are just like you
in many ways.

They like to play, learn, and have fun, just like any
other kid.

They might need some extra help with certain things,
but they're still amazing friends who deserve
kindness and understanding, just like everyone else!





It's important for people to learn about PWS
so they can understand and support those
who have it.

By spreading awareness and showing
kindness, we can create a more inclusive and
understanding world for everyone, including
those with Prader-Willi Syndrome.



Thank you for learning
about
Prader-Willi Syndrome

