

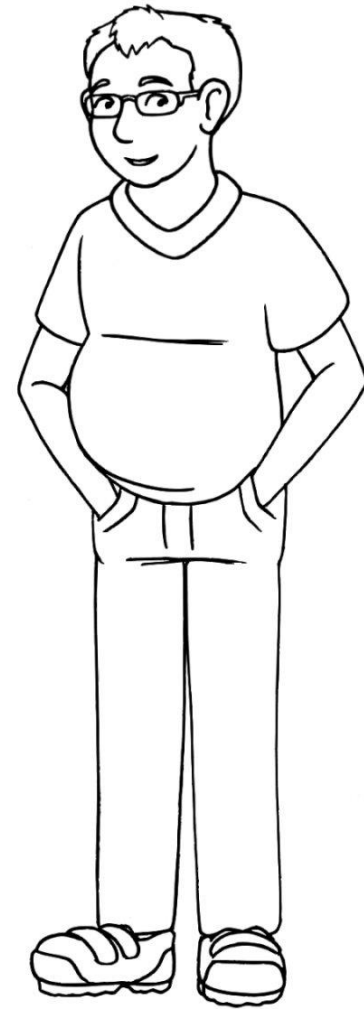


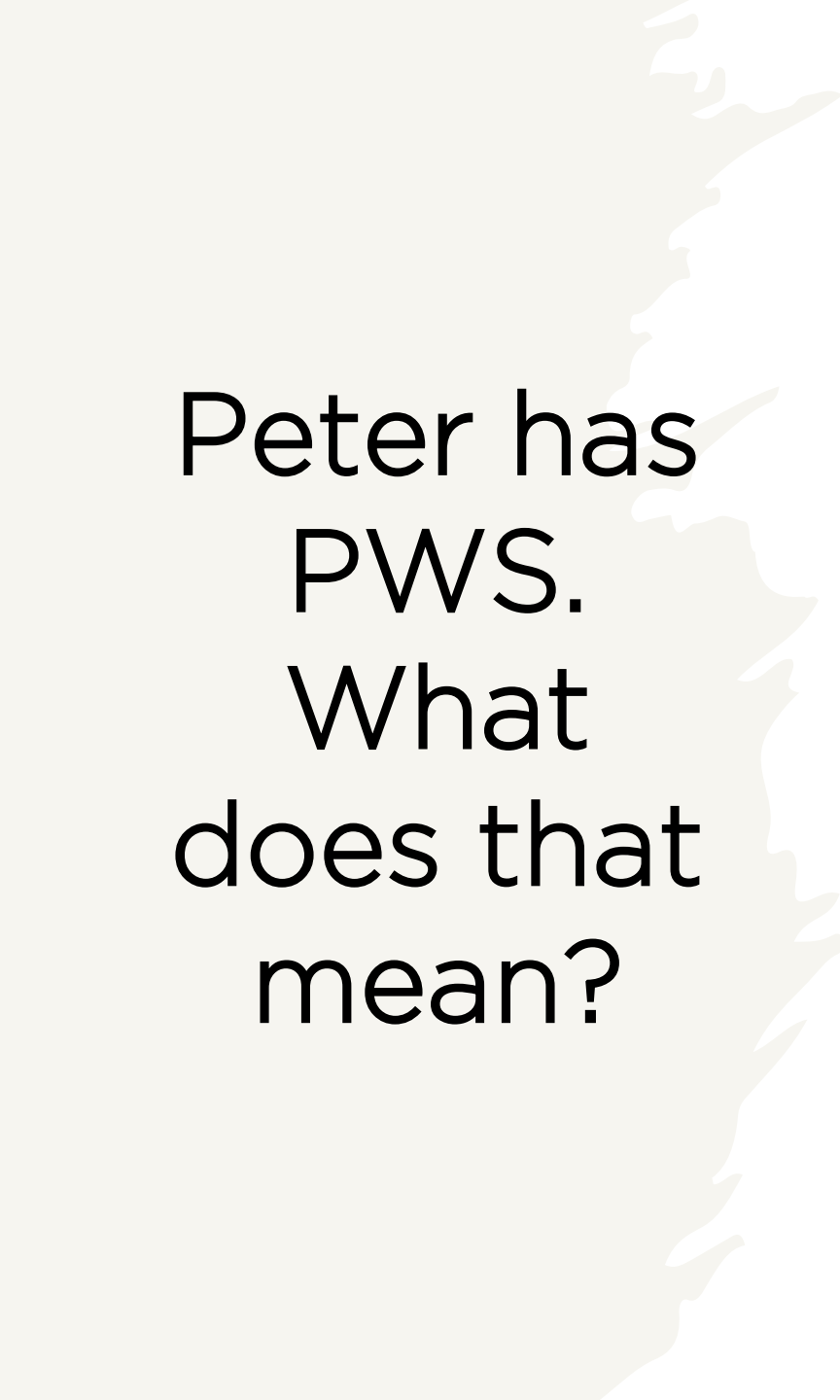
Let's talk about PWS

A workbook about Prader-Willi
Syndrome



This is Peter...





Peter has PWS. What does that mean?

If you have a syndrome, it means you show signs that something is different or special about you. If you have PWS you have a medical condition that means you might behave and feel differently to people who don't have PWS.

Prader-Willi Syndrome is a special kind of syndrome. If you have it, you are born with it and will have it for your whole life. It's quite rare to have PWS and it happens completely at random.

It's also a special syndrome because of its very unusual name which comes from the Doctors who first recognised it- Dr Prader and Dr Willi, who lived in Switzerland.

How is Peter similar to you?

Activity

Colour the things that you and Peter have in common

Peter likes to go swimming

Peter eats special, healthy foods

Peter sometimes gets cross when things change

Peter loves his family lots and lots

Peter is good at jigsaw puzzles

Peter finds it difficult to choose between different things

PWS and You

Let's find out what sort of things we need to do in order to stay fit, healthy and happy with PWS.

I wonder if Peter can help us along the way?...



Healthy Foods

People with PWS feel hungrier than people who don't have PWS, and it can be difficult for you to feel full for very long.

This can sometimes mean that people with PWS spend lots of time thinking about food. That's why it's important for people with PWS to have lots of activities to do throughout the day, so they have lots of other things to focus on.

Most of the time, people with PWS will have a healthy eating routine, and it's important to stick to this so that you stay fit and healthy.

Peter Says:

'Each and every one of us eats different foods and everyone should eat healthy foods if they want to be fit'

Special Medicine

If you have PWS, you might be shorter than other people your age.

However, if you take a special medication called Growth Hormone, you might be just as tall, if not taller!

You might have smaller hands and feet too.

Having PWS means you have something called Low Muscle Tone. This means it's difficult for you to build strong muscles. Peter's special medicine helps him to grow strong too.

Peter says:

'Each and every one of us comes in different shapes and sizes'

Exercise

As well as eating healthy, people with PWS have to make sure they are getting enough exercise.

Everyone needs the right exercise, even though lots of people don't get enough to stay fit and healthy.

Making sure you do lots of fun activities like playing sports or swimming will keep you strong and healthy.

Peter Says:

'Each and every one of us needs regular exercise!'

Tick the things you like to do to stay fit and healthy

- | | | | |
|----------------|--------------------------|----------------|--------------------------|
| • Football | <input type="checkbox"/> | • Gymnastics | <input type="checkbox"/> |
| • Cricket | <input type="checkbox"/> | • Running | <input type="checkbox"/> |
| • Tennis | <input type="checkbox"/> | • Basketball | <input type="checkbox"/> |
| • Trampolining | <input type="checkbox"/> | • Netball | <input type="checkbox"/> |
| • Swimming | <input type="checkbox"/> | • Hockey | <input type="checkbox"/> |
| • Walking | <input type="checkbox"/> | • Table tennis | <input type="checkbox"/> |
| • Dancing | <input type="checkbox"/> | • Beach games | <input type="checkbox"/> |



Talking to others

Sometimes people with PWS might find it difficult to speak to other people and communicate.

This could be for lots of reasons. Sometimes, it might be hard to understand your emotions and feelings.

Also, because of low muscle tone, it's sometimes hard to work the muscles around the mouth making it difficult to get your words out. You might meet with someone called a Speech Therapist who can help with this.

Lots of other people who don't have PWS might find communicating difficult too, so you're not alone!

Peter Says:

'Each and every one of us has their own way of communicating'

Listening to others

When other people are talking to you, you might find it difficult to understand what they are trying to say, or it might take you longer to work out what they mean. This is called processing.

Some people can process information quite fast, whereas other people take longer.

Some people prefer to look at pictures rather than read words and that's fine!

There are lots of ways to understand what other people are trying to say, you just have to work out which ones work best for you and ask other people to use these instead.

Peter Says:

'Each and every one of us listens and learns in different ways'

Routines and change

Most people with PWS like to have a routine, so they know what to expect and what is happening next.

Lots of people who don't have PWS like this too and most of us can get upset if something changes at the last minute.

Change often means that something is coming to an end, which can make us sad, but we often forget that this also means something new and exciting is about to start.

Sometimes, it isn't possible for everything to go exactly to plan and we need to change certain things or activities. Then our other plans can go ahead.

Peter says:

'Each and every one of us struggles with change and can worry about what is coming next'

Feelings

Sometimes, with all these challenges you face each day, you might start to feel sad, anxious or upset and sometimes it might be difficult for you to tell someone about this.

This means you might become angry or frustrated. Most people with PWS will have someone to support them with this. Maybe your Mum or Dad, a different relative or a support worker.

They might be able to tell when you are getting upset, but they might not. If you can tell someone “I’m feeling sad”, they will be able to help you before you lose your temper.

If you do lose your temper, it’s a good idea to think about WHEN this has happened so you and your family/carers can work out WHY it happened. Then you can work together on avoiding it in the future.

Peter says:

‘Each and every one of us feels angry from time to time’

Draw a picture in the box to show
what makes you...

Sad



Angry



Happy



Laugh



Challenges

People with PWS often have lots of talents but can find other things quite difficult, just like everybody else.

For example, you might be very good at crafts and puzzles but find maths more difficult.

We all have different strengths and weaknesses and even though it might be frustrating, it's ok when you need to ask for help.

Peter says:

'Each and every one of us needs to ask for help sometimes'

Who helps you...

At home?

What do they do to help you?



At School?

What do they do to help you?

Being super special!

What's really special about people with PWS is that they can show love and affection, and often find this much easier than other people do.

Telling someone you love them or giving someone a hug always makes them feel good about themselves and people with PWS tend to be very good at this.

People with PWS also tend to be good fun and are able to make people laugh.

Peter says:

'Only YOU have this special set of skills'

What have we learned?



Having PWS makes *some* things about you different, but everybody is different!

We all find different things difficult and we all have different talents.

Peter thinks that's what makes the world a special place. Do you agree?

Colour in the pictures that show something that you find difficult



Talking to others



Joining in with others



Understanding what others mean



Waiting for things



Understanding how you feel

Colour in the pictures that show things that other people can do to help you



Use actions or pictures



Keep food out of sight and reach



Be patient and calm



Repeat what they have said



Show you what to do

Sometimes you might feel angry or upset.

We all feel angry from time to time and this is ok, but its not ok to hurt other people.

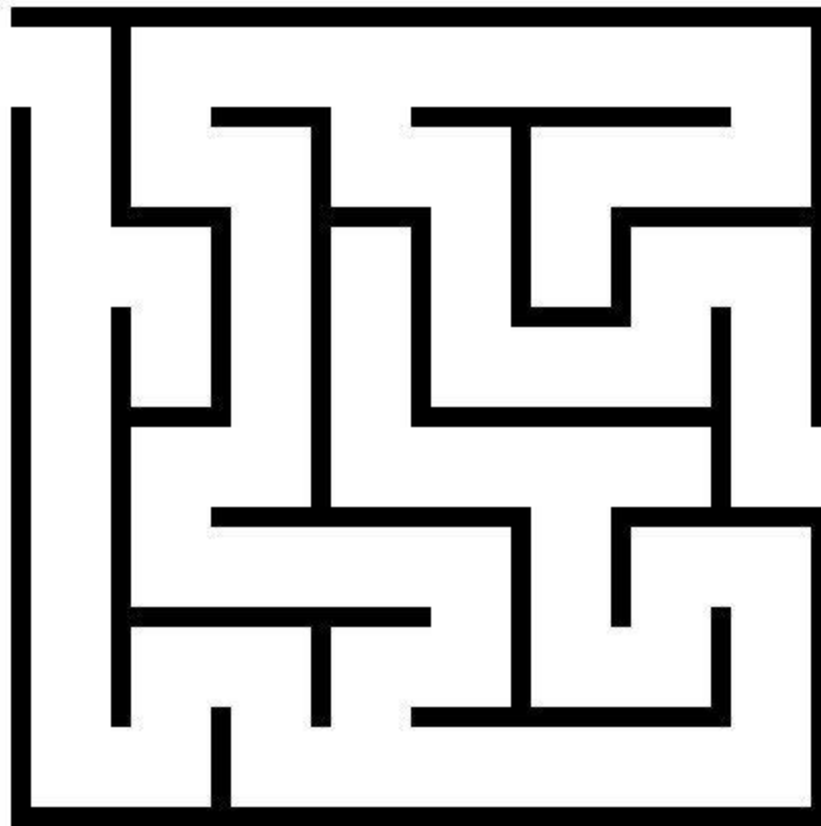
What sort of things might we do when we're angry that could hurt other people? How might it make them feel?

Shouting at people makes them feel.....

Hitting people makes them feel.....

Saying nasty things makes them feel.....

Can you help Peter find his way home from school?



Wordsearch

It's time for Peter to go to bed. Can you find all these “nighttime” words?

Dreams

Tooth brush

Pyjamas

Teddy

Soap

Story book

Nightlight

Moonlight

Sleep

W	V	C	N	O	T	R	U	S	T	M	M
A	F	L	H	S	U	B	X	K	O	T	X
Z	B	T	H	G	I	L	N	O	O	M	P
P	A	D	R	E	W	P	D	J	T	K	T
L	O	C	R	V	A	N	H	O	H	W	V
H	A	P	P	E	Y	S	I	N	B	T	I
A	B	E	N	M	A	I	L	L	R	I	E
B	A	I	T	L	Y	M	N	A	U	R	O
R	A	H	E	N	R	S	S	Y	S	E	L
I	N	I	G	H	T	L	I	G	H	T	Z
A	B	E	T	H	J	E	A	N	E	C	H
R	I	S	H	A	R	E	R	Y	C	S	H
A	T	E	D	D	Y	P	R	K	I	O	E
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PO Box 8478
Derby
DE1 9HT

T: 01332 365676
E: admin@pwsa.co.uk
W: www.pwsa.co.uk