

## The Newsletter for Adults with PWS Written by Adults with PWS



***Stuart's amazing  
rowing challenge!***



## Hello everyone!

I hope you all had a very happy Easter. Isn't it lovely to see the spring flowers coming out and the trees coming into leaf? I love this time

of year when the nights stay lighter for longer. This is a great time to start getting some outdoor exercise although you might still need your wellies on as the ground is so wet after all the rain we've had this year

I have been gardening and it's a really good way to stay fit and healthy. Walking is good too and sometimes I walk up to my local park where they have some outdoor gym equipment for adults! It's great fun.

In the news magazine for parents, we have information about some more characteristics of Prader-Willi syndrome, and we have been looking at **hypotonia** or low muscle tone. This means that your muscles aren't as strong as the rest of the population although plenty of people with PWS take part in lots of healthy exercise including trampolining, horse riding and swimming.

For some of you, low muscle tone can make walking and exercising feel difficult and it can cause tiredness. Even if this is the case, gentle exercise is important to stay fit, and it helps to keep your weight down too.

We've also looked at sleep problems and I know that some of you will have **sleep apnoea**. Sometimes this means that you need to wear a special oxygen mask while you sleep. I imagine it must be difficult to do this. You might still have a sleep study at home or in hospital to check your sleep apnoea.

Lots of you will also have something that doctors call EDS or excessive daytime sleepiness. This can be due to being a very light sleeper and not getting a full night time rest.

**If you want to find out more about these two things, you can call our Specialist Advisor Team on 01332 365676.**

*Ruth*





## Ryan's first work certificates!

Ryan Inwards has been attending Steps to Work since Christmas and has received his first two certificates. Steps to Work is a supported employment service within Adult Social Care and Health which forms part of East Sussex County Council's Learning Disability services.

This service helps and supports people with a learning disability and/or autism into work. They currently offer community-based projects including a car cleaning valet service, as well as work placements with local employers throughout East Sussex.

### Ryan explains what the certificates are for:



I am half way through my Steps to Work course. I attend this every Wednesday with my work mentor and have work books to complete. In the picture I have finished two workbooks and got the certificates for them.

The first certificate is for understanding what to do if things are making me sad or angry at work. It looks at things that may go wrong like not liking how someone talks to me or treats me, how to do the right thing and not get angry or upset.

I talked to my mentor and wrote about talking to my mentor or to someone at work and not letting it get bad. I know the best thing to do is to tell the person I don't like what they are doing or saying. If they don't stop then I would talk to the boss. I know it is important to write down dates and times they have been horrible and things they say. I also know that sometimes not everyone can like everyone and I will have to see if things get better as well. If it is my boss who is being horrible to me then I would talk to his boss and my mentor.

The other certificate is for when things with my work go wrong and what to do. I know it is very important to make sure I understand what the boss is asking me to do. I will explain to him sometimes I do not understand and he may have to say it differently. I know it is important not to pretend to understand as this means I might do something wrong. I know my boss will like me if I tell the truth and not pretend. If I get stuck I will talk to the boss or the person the boss has told me to go to. I know I have to do this straight away and not sit and worry. Sometimes it maybe the boss telling me I have done something wrong and I know it is important not to get angry or upset and ask him to tell me how to do it better.

In the workbooks and at college they tell me things I can say and how to say things so people understand.

I am really enjoying this course and hope when I finish I will get a job. I want to work with children or animals.

# Our Positive News

## Stuart's amazing rowing challenge!



Stuart Mitchell was given a challenge over Christmas, with the reward being a two-week holiday to Spain. The challenge started on Christmas Eve and was initially to burn 600 calories a day on the rowing machine or the exercise bike for a month.

It quickly turned into a competition with his youngest brother. His brother set daily targets for Stuart to try and beat. This started with 7km on the rowing machine which Stuart easily surpassed. Next day was 9km then 11km and then 13km. Each day, Stuart beat the target but instead of just beating 13km he did 17.5 km and set the challenge for his brother instead. Then his brother set a challenge of 1,029 calories. Never thinking Stuart would reach this, his brother relaxed. Within two hours the photographic evidence proved Stuart had done 18.2 km and burned 1,032 calories!

## Sunflower lanyards



Thanks to an amazing suggestion from the Owl Focus Group of adults with PWS, we have joined the Hidden Disabilities Sunflower and developed a Sunflower lanyard and information card specifically for our community at PWSA UK.

The Owl Focus Group wanted the lanyard to show they have a disability, and if a situation arises in public, it isn't them but their PWS. This really resonated with us, which is why we have worked so quickly to provide bespoke lanyards and Sunflower cards.

The lanyard and card are sold together and cost £5.95 including P&P. Get yours now at [pwsa-uk.ecwid.com](http://pwsa-uk.ecwid.com)!



## Lucy's busy life!

### Lucy Taylor shares her latest news

I am volunteering at Auchingarra Wildlife Centre every Wednesday from 10am till 2pm, with my new two experienced support workers.

I go and help out with the animals like mucking out giving them food and water. I have helped with the meerkats, male goats, wallabies, emus, guinea pigs and chickens, collecting their eggs.

This week I'm helping out with the donkeys and every Wednesday I get to feed the baby lambs and cuddle them. I have bonded with the lambs.

Because I'm helping out with the animals, I get a free lunch every Wednesday. I get soup and a sandwich and a drink for helping.

I'm really enjoying it. I love it. I got to name one of the new baby lambs and I called him Blue. I was chuffed that I got to pick the name for him.

I will be having my assessment some time later this month for my supported living. I'll maybe have my own flat on a block with others with disabilities. I'm really excited and hopefully I'm leaving home when I'm 21. That's what I wanted to do - I'm so excited.

My family is so proud of me just now as I lost my great gran who was close to me and I know she hasn't got dementia anymore so I'm being grown up about it just now.

I know I was extremely upset when I got the news, but I took the news really well as I know she is in peace and she hasn't got dementia.



I know a lot of people with PWS don't understand what dementia is and I'm going to explain to you so you can understand.

Dementia is when you lose your memory and can't remember anything. You can't look after yourself and hygiene and need to be cared for at home or in a care home and not know your family and it makes you feel tired and you sleep a lot.

It's a horrible disease. It's a bit like PWS, like our brain works differently than people without PWS, but we can look after ourselves and hygiene, we get help with our time keeping and money management to keep us safe.

Sometimes we do wrong things but don't worry, it's not our fault it's our PWS.

We have low muscle tone which means we get very tired easily more than others without PWS. We need help to control our eating but remember it isn't us that's doing it, it's the PWS and sometimes we do something bad but our parents don't go mad at you because they understand you don't mean it but you will get less if you have any extras.



# Book reviews



**with  
Ruth**

You might remember that one of our members, Fran, used to do a book review in the magazine, and we thought it might be something you would like to see. Have a look at our selection below.

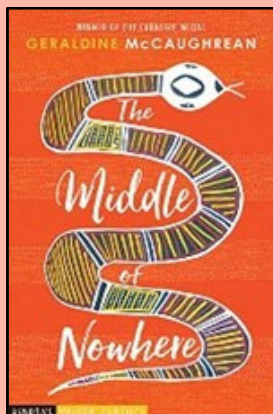
I know that books can be expensive to buy so if you have a library near by you might want to think about joining. It's free and you can usually take out 6 books at a time and keep them for up to 3 weeks. Be careful not to go over the time you're allowed to keep them, as you will end up getting a fine and it could cost you a few pounds.

Lots of charity shops sell second-hand books so if you love reading these are good places to visit. Or you could set up a book swap in your setting if you live with others.

If you like to read on a Kindle or use the Kindle app on your phone, you could sign up to 'Book Bub'. They will send you emails once a week with a selection of books and their prices are really good, usually 99p to £1.99 and quite a lot of them are free! When you sign up, you can choose which sort of books you like to read. Like, crime, romance, fantasy, sci-fi and non-fiction as well.

If you would like to write a review of a book or a film you have watched, we'd love to hear from you!

## ***The Middle of Nowhere* by Geraldine McCaughrean**

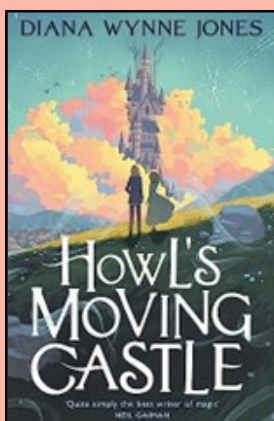


Comity's life in the Australian outback changes forever. When her mother dies from a snakebite, As her father retreats into his work, Comity turns to Fred, the Aboriginal yard boy, who becomes her only friend. But then a new assistant arrives who delights in playing cruel games. As Fred becomes his target, events spiral dangerously out of control.

## ***The Paper Magician* by Charlie N. Holmberg**



Ceony Twill arrives at the cottage of Magician Emery Thane with a broken heart. Having graduated at the top of her class from the Tagis Praff School for the Magically Inclined, Ceony is assigned an apprenticeship in paper magic and once she's bonded to paper, that will be her only magic...forever.



## ***Howl's Moving Castle* by Diana Wynne Jones**

Sophie Hatter from the land of Ingary catches the unwelcome attention of the Witch of the Waste and is put under a spell . . . Deciding she has nothing more to lose, Sophie makes her way to the moving castle that hovers on the hills above her town, Market Chipping.

But the castle belongs to the dreaded Wizard Howl, whose appetite, they say, is satisfied only by the souls of young girls...



**Happy birthday to everyone who will be celebrating between now and the next Wise Owl Feathers!**

**What are you doing to celebrate? Let us know - and don't forget to send us photos so that we can share them here in Wise Owl Feathers!**

# Colouring Time & Wordsearch



## Anagrams

Can you unscramble the letters below to make words related to footwear? Two words in the clue = a two-word answer.

1. betall hoses \_\_\_\_\_
2. glosc \_\_\_\_\_
3. cie steaks \_\_\_\_\_
4. plif-splof \_\_\_\_\_
5. lorrel askset \_\_\_\_\_
6. kis stoob \_\_\_\_\_
7. prisslep \_\_\_\_\_
8. smupp \_\_\_\_\_
9. gashsole \_\_\_\_\_
10. setitslot \_\_\_\_\_
11. wasred \_\_\_\_\_
12. scamsonic \_\_\_\_\_



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

## Flower wordsearch

Can you find the names of the following flowers in the grid?

CARNATION

POPPY

FOXGLOVE

GLADIOLI

PEONY

DAFFODIL

ORCHID

ROSE

DAISY

CHRYSANTHEMUM

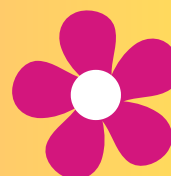
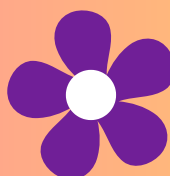
MARIGOLD

AZALEA

LILY

SUNFLOWER

TULIP



## Quiz

1) Which sport is played at The Oval?

- a. Football
- b. Tennis
- c. Cricket

2) Which country gave the Statue of Liberty to America?

- a. Egypt
- b. France
- c. Spain



3) What is the name of this famous building?



- a. Taj Mahal
- b. The White Temple
- c. The Three Domes

4) Which of the following is a faun in The Lion, The Witch & The Wardrobe?

- a. Mr Trumpkin
- b. Edmund
- c. Mr Tumnus

5) What is a baby goat called?

- a. Kid
- b. Pup
- c. Calf

6) Which country does this flag belong to?



- a. China
- b. Mexico
- c. Canada

7) How many pockets does a snooker table have?

- a. Four
- b. Eight
- c. Six

8) Which sport is Emma Raducanu famous for?

- a. Tennis
- b. Golf
- c. Running



**WINNER! Congratulations to the winner of last issue's quiz, Kimberley Taylor. A prize is on its way to you!**

Send your answers to the quiz and your completed wordsearch by 10th June 2024 to:

**PWSA UK c/o Metcalf's Commercial Decorators,  
3 Deer Park Road, Moulton Park, Northampton,  
NN3 6RX**

Name\_\_\_\_\_

Address\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**Please make sure you put the correct postage on your envelopes, including checking that your stamps have barcodes!**