FOWLER'S SYNDROME AND ANXIETY

Introduction to CBT



FOWLER'S SYNDROME UK

IS THIS BOOKLET **RIGHT FOR YOU?**

For many people, having Fowler's Syndrome / Chronic Idiopathic Urinary Retention (CIUR) is one of the toughest experiences they will have to face. The years leading up to and after diagnosis can be a very stressful and anxiety-inducing time, not just for the person with Fowler's, but for anyone who cares about them.

This is a short booklet for women with Fowler's Syndrome / CIUR who may also have anxiety. The booklet suggests ways to help you manage worry and uncertainty around your symptoms and diagnosis. It contains an introduction to anxiety, a summary of what happens in Cognitive Behavioural Therapy (CBT), a series of exercises, ways that a trained psychologist could help, and advice on how you can help yourself. It also has information about where to get help and support.

This booklet is **not** intended to replace therapy. Therapy is best delivered by a qualified, experienced psychotherapist. We hope the booklet will be of interest to those who are curious to know how therapy can help or for those who are seeking therapy but are on a waiting list. There is a section at the end which sign-posts further resources.

Please contact us on hello@fowlerssyndrome.co.uk if you need further support.

IS THIS BOOKLET **RIGHT FOR YOU?**

We have created this booklet because we believe there is a gap between the provisions for women with Fowler's Syndrome, and the help that they actually need.

77% of women with FS/CUIR report seeing more than four clinicians before diagnosis, feeling largely unsupported and often dismissed, with over three quarters feeling their symptoms were deemed 'imaginary' or 'all in their head'. Fowler's syndrome profoundly affects quality of life, with most women rating it as severe or devastating. Dating and sexual intercourse are the most impacted (97% severe), followed by work (83% severe) and socialising (81% severe).

E R COX, J N PANICKER, D COOMBE, C SELAI, D ELLIS, J STONE, & I HOERITZAUER (2024) FOWLER'S SYNDROME: PATIENT LED PHENOTYPING OF 265 PATIENTS (SUBMITTED).

CBT CASE STUDY

We have included this short case study from an NHS Health Care Professional with Fowler's syndrome, to demonstrate how CBT can be an effective way for people to manage their anxieties and emotions, and how knowing what you want to achieve from CBT can help you and your therapist work collaboratively towards positive outcomes.

I have had CBT a few times over the years, with the first in 2015. I was completing my nursing training and my Endometriosis was severely impacting my life and studies. Was it helpful? Actually, I did not find it helpful at that time. Maybe it was partly my immaturity (aged 21 I am now 31), or their lack of understanding of how my condition truly impacted me.

In 2020, I was working in intensive therapy units during the pandemic. My Fowlers was in full flow. Wearing PPE, little breaks, no toilet breaks to avoid 'wasting' PPE. It was devastating. I would pack extra underwear in case I had an accident. Here I was caring for the sick and dying and I was stressed about soiling myself, endometriosis flares and wasting PPE. Amongst other things, this severely impacted my mental health.*

*PERSONAL PROTECTIVE EQUIPMENT

So I signed up to CBT again. This time, it was helpful. Maybe it was because my therapist really cared about me. She listened, remembered and invested herself into my concerns and emotions. She reassured me, built up my self confidence and gave me pointers. Not for my conditions, but my emotions. Still now, I use the skills strategies that I learned. I carried out these sessions online and continued to do so after the pandemic. For me this was helpful, it fitted around my work pattern, it was flexible.

Over my various stints of CBT and my experience as a healthcare professional, therapy only works if you have a personal goal. Elaborate exactly what you want out of it. What you need out of it. With that, you will accomplish what you set out with the help of a therapist

Please feel free to explore this booklet to gauge a better understanding of how CBT (alongside a professional) can help you manage worries and other emotions which relate to Fowler's Syndrome / CIUR.

YOU SHOULD SEEK **ADVICE FROM YOUR DOCTOR IF:**

1. You are experiencing strong urges to self harm.
2. You are experiencing symptoms of trauma, including flashbacks, nightmares and avoidance.

TRIGGER ALERT:

Some sections of this booklet may trigger strong emotions or cause upset. If you are feeling any emotional distress from completing this booklet, please stop. If you need support, you can contact your GP, 111, or the Samaritans by calling 116 123.

WHAT IS **FOWLER'S SYNDROME?**

Fowler's Syndrome is a condition in which women have problems passing urine, often resulting in chronic urinary retention. This arises due to difficulty relaxing the urinary sphincter and coordinating urination which can result in the need for a catheter.

To confirm the condition and rule out other causes, women are likely to require investigations such as urodynamics, urethral pressure profiling and/or EMG studies.

The condition is often associated with recurrent urinary infections and gynaecological conditions such as polycystic ovary syndrome and endometriosis. 90% of women with Fowler's have urethral pain, 89% have bladder pain and 76% of women experience pelvic pain.

A 2022 survey conducted by Fowler's Syndrome UK found that out of 265 women with the syndrome:

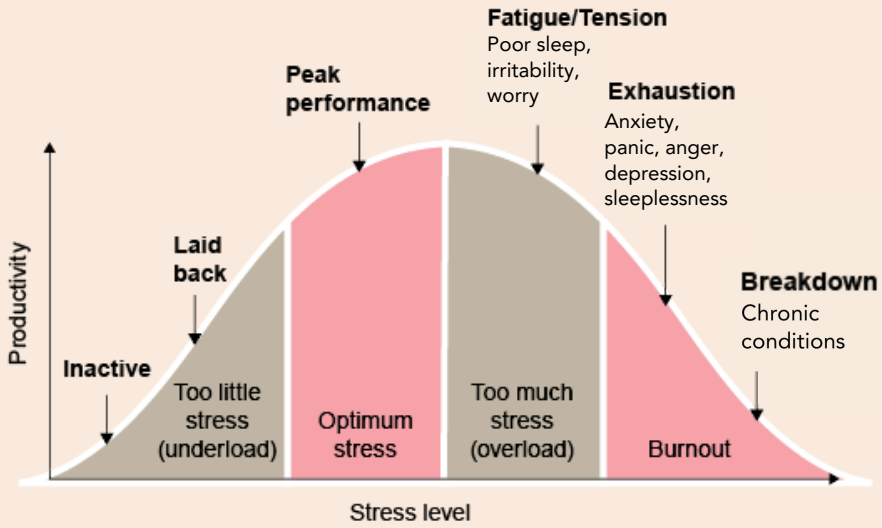
79% WERE DIAGNOSED WITH ANXIETY
70% WERE DIAGNOSED WITH DEPRESSION
48% WERE DIAGNOSED WITH POSTTRAUMATIC STRESS DISORDER (PTSD)

E R COX, J N PANICKER, D COOMBE, C SELAI, D ELLIS, J STONE, & I HOERITZAUER (2024) FOWLER'S SYNDROME: PATIENT LED PHENOTYPING OF 265 PATIENTS (SUBMITTED).

WHAT IS **ANXIETY?**

ANXIETY IS THE BODY'S RESPONSE TO SITUATIONS WHICH ARE VIEWED AS THREATENING.

According to the Yerkes-Dodson Law, a certain amount of anxiety can be beneficial. However, too little or too much anxiety can be harmful.



Here is an example of how different levels of anxiety can affect a person's life.

Situation: You are preparing for an important presentation at work in front of your colleagues and supervisors

No Anxiety	Moderate Anxiety	High Anxiety
A presentation you say? Eh, whatever. I'll wing it.	I know I can do this, but I need to be prepared. I'll prepare extra supplies and inform a trusted colleague about my CIUR.	This is too much. What if I experience urinary retention during the presentation and need to leave? I feel sick just thinking about it - I can't do it.

WHAT IS **CBT?**

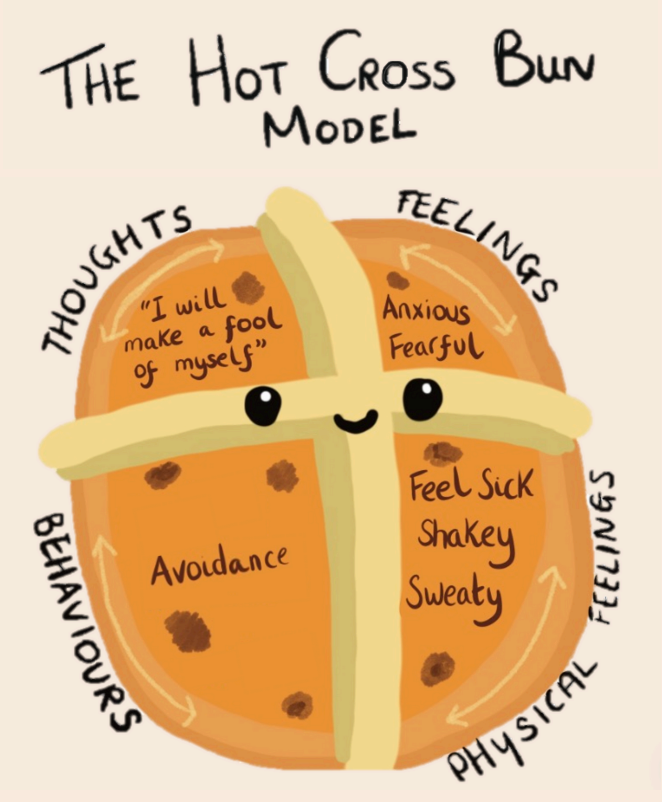
One helpful psychological approach to manage anxiety is called Cognitive Behavioural Therapy (CBT), which can help you manage your problems by changing the way you think and behave.

CBT HELPS US UNDERSTAND THAT OUR THOUGHTS, FEELINGS, EMOTIONS AND BEHAVIOURS ARE INTERCONNECTED

CBT breaks down overwhelming problems into manageable parts, helping individuals modify negative patterns and cultivate a positive mindset.

Unlike therapies focused on the past, CBT addresses current issues, offering practical strategies for daily improvement.

Proven effective for various mental health conditions and long-term health issues, CBT assists individuals in coping with symptoms and enhancing overall well-being.



CBT can involve setting goals, keeping notes and diaries. On the next page, we will introduce a 'thought log', which is one way to manage your anxiety.

INTRODUCING A **THOUGHT LOG**

Here is an example of how two people can experience the same situation in different ways, depending on their thinking style.

A FAMILY ARE PLANNING A HOLIDAY TO A REMOTE MOUNTAIN CABIN, WHERE THERE WON'T BE MEDICAL FACILITIES NEARBY.

SOPHÍA

NEGATIVE THOUGHT: "WHAT IF I GO INTO RETENTION WHILE WE ARE UP IN THE MOUNTAINS? WHAT IF SOMETHING GOES WRONG, AND I CAN'T GET THE MEDICAL HELP I NEED? I'LL BE IN SO MUCH PAIN AND WON'T BE ABLE TO COPE. I'LL RUIN THE WHOLE TRIP FOR EVERYONE AND THEY'LL BE UPSET WITH ME. IT'S TOO RISKY; I CAN'T GO".

EMOTION: DEPRESSED AND NERVOUS.

BEHAVIOUR: SOPHÍA DECIDES TO CANCEL HER TRIP AND AVOID THE SOCIAL SITUATION.

AISHA

RATIONAL THOUGHT: "I'VE MANAGED FOWLER'S SYNDROME BEFORE. I'LL PACK EXTRA SUPPLIES, INFORM MY FAMILY ABOUT MY CONDITION, AND ENSURE WE'RE PREPARED. WITH GOOD PLANNING AND COMMUNICATION, WE CAN STILL ENJOY OUR VACATION".

EMOTION: CONCERNED BUT CONFIDENT.

BEHAVIOUR: AISHA DECIDES TO GO ON HOLIDAY AND ENGAGE IN PROACTIVE PLANNING AND COMMUNICATION.

A thought log consists of prompts to help us see that the way we think, feel and behave are all linked and continuously affect one another.

Thought

We all have automatic thoughts. These can be interpretations of a situation, yourself or others.

Emotions

What emotions do you feel as you have these thoughts?

Physical Sensations

You may experience physical sensations due to these thoughts.

Behaviours

How did you respond to a situation, based on your thoughts and feelings?

MEET SARAH

Sarah is a 25 year old woman who experiences chronic urinary retention.

Since she was diagnosed a year ago, she's been cancelling her friends' requests to go out and has been withdrawing from her friendship group- who she used to see often to confide in. She loves the idea of spending time with them, but experiences anxiety when she thinks about it for too long.

THIS IS HOW I FILLED IN A THOUGHT LOG TO GET A BETTER UNDERSTANDING OF HOW I FEEL. YOU CAN DO THE SAME ON THE NEXT 2 PAGES.



	PROMPT	DAY 1
Thought We all have automatic thoughts. These can be interpretations of a situation, yourself or others.	THOUGHTS	When I go out for a meal with my friends, I feel like they all notice that I take such a long time in the bathroom and judge me for it... I feel like they're better off without me ruining the mood.
Emotions What emotions do you feel as you have these thoughts? Does it change your mood or intensify any pre-existing feelings?	EMOTIONS	• Embarrassed • Self-conscious of bladder • Worry that they find me annoying because when I finally go out, I'm not able to sit for long.
Physical Sensations You may experience physical sensations due to these thoughts.	PHYSICAL SENSATIONS	• Bladder pain • Fidgeting or bouncing my leg • Heavy breathing
Behaviours How did you respond to a situation, based on your thoughts and feelings?	BEHAVIOURS	I've been cancelling on my friends a lot more recently. I've become less social and have spoken to my best friend less and less.

THOUGHT LOG

	DATE: / /	DATE: / /	DATE: / /
PROMPT	DAY 1	DAY 2	DAY 3
THOUGHTS			
EMOTIONS			
PHYSICAL SENSATIONS			
BEHAVIOURS			

NOTES:

THOUGHT LOG

	DATE: / /	DATE: / /	DATE: / /
PROMPT	DAY 4	DAY 5	DAY 6
THOUGHTS			
EMOTIONS			
PHYSICAL SENSATIONS			
BEHAVIOURS			

NOTES:

UNHELPFUL **THINKING STYLES**

Sometimes, we develop patterns of thoughts or behaviours that are unhelpful. Below are some unhelpful thinking styles and examples. Tick the thoughts you've had in the past 2-3 weeks.

Unhelpful thinking style	Example of typical thoughts	✓
Negative mental filter: Putting a negative slant on things	I see things through dark-tinted glasses / in a negative way	
	I see the glass as being half empty rather than half-full	
	Whatever I've done in the week it's never enough to give me a sense of achievement	
	I tend to focus on the bad side of everyday situations	
Catastrophising: Jumping to the worst conclusion	I tend to predict that the very worst outcome will happen	
	I'm going to collapse	
	If my partner / family member is late home, I think they have had an accident	
Bias against myself: Putting myself down	I'm very self-critical	
	I overlook my strengths	
	I see myself as not coping	
	I don't recognise my achievements	
	Other people would cope better than me with this	
Mind reading: Negative view about how others see me	I mind-read what others think of me	
	I often think that others don't like me/think badly of me without evidence	
Bearing all responsibility	I think I should take the blame if things go wrong	
	I've brought this on myself. It's all my fault	
	I think I am responsible for everyone else	
Making extreme statements/rules	I use the words 'always' and 'never' a lot to summarise things	
	If one bad thing happens to me I often say 'Just typical' because it seems this always happens	
	I make myself a lot of 'must' , 'should' , 'ought' or 'got to' rules	
	I should just be able to put this all behind me and return to normal	

TASK 1
DECATASTROPHISING

One common unhelpful thinking style is Catastrophising. This activity below may help you to stop these extreme thoughts by considering realistic potential outcomes.

What are you worried about?

How likely is it that your worry will come true? Give examples of past experiences, or other evidence to support your answer.

If your worry does come true, what's the worst that could happen?

If your worry does come true, what's most likely to happen?

If your worry comes true, what are the chances you'll be okay...

In one week? _____%
In one month? _____%
In one year? _____%

TASK 2
CHALLENGE THOUGHTS

Immediate thoughts come and go very fast, and are not always the most balanced. This is why it is important to challenge any thoughts which cause us harm.

Thought to be questioned:

What is the evidence for and against this thought?

Are you basing this thought on facts, or feelings?

SPEND A MOMENT THINKING ABOUT EACH QUESTION, TO EVALUATE HOW YOUR THOUGHT WEIGHS UP AGAINST EVIDENCE.

Are you making any assumptions when you interpret the evidence?

Has your thought changed after you challenged it?



GROUNDING TECHNIQUES

You may be experiencing flashbacks from trauma, or other symptoms of PTSD.

To help you in overwhelming moments, you can use grounding techniques. They can help bring us back into the here and now - in a way that feels **safe**.

Progressive Muscle Relaxation

Notice the sensations you feel during tensing and relaxing.

- Tense and relax each muscle group, starting from your toes to your head.
- Tense for 5 seconds, then let go and relax the muscle fully.

5-4-3-2-1

Using your senses can bring you into the present moment.

- Name 5 things you can see.
- Name 4 things you can hear.
- Name 3 things you can touch. within your immediate reach.
- Name 2 things you can smell.
- Name 1 thing you can taste.

Physical Grounding

Reflect on where your body is in the present moment.

- Place both feet on the ground.
- Clench your hands into fists, then release the tension.
- Gently tap your shoulders, alternating one side at a time.

Box Breathing

Focus on how it feels to fill your lungs with air, and the relaxation that comes with slowly exhaling.

Breathe in to a count of 4

Hold for a count of 4

Breathe out to a count of 4

Pause of a count of 4

NEXT **STEPS**

The ISEO is an online guided self-help resource where people can chat 'live' online with a therapist whilst working through the content at their own pace. The service is free for many NHS patients in the UK and the website lets you check if it's available to you. You can access it here: https://www.iesohealth.com/how-it-works

You can search for an NHS talking therapy service here: https://www.nhs.uk/service-search/mental-health/find-an-nhs-talking-therapies-service

FURTHER **READING**

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- Rothschild, B. (2000). **The body remembers the psychophysiology of trauma and trauma treatment.** New York London W. W. Norton & Company.
- Van der Kolk, B. (2015). **The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma.** Penguin Books.

With thanks to our patient partners and Fowler's foxes who have given their time and expertise to this project. Urinecredible.

Please let us know how you got on! For example, what did you find helpful and are there any improvements we could make?

GET IN TOUCH

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Uzma is a final year BSc Psychology student, who has begun developing expertise in the Clinical Psychology field - particularly regarding mental health and trauma.

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Dani is the founder and CEO of Fowler's Syndrome UK, the first charity in the world for women with Fowler's Syndrome.

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Dr. Selai is a psychologist and therapist based in the clinical department of Uro-neurology, The National Hospital for Neurology and Neurosurgery. Also Honorary Associate Professor, UCL. She set up a psychology service in the department of Uro-neurology.