Explaining my diagnosis: primary enuresis

ERIC Young Champion George explains his diagnosis of primary enuresis *and the stigma and misunderstandings around the condition. I am George: I have primary enuresis and I am autistic.*

What is primary enuresis?

- Primary enuresis is the medical term for involuntary bedwetting during sleep.
- It normally means that the child or young person isn't able to sleep through the night without bedwetting. Normally they do not have daytime symptoms.
- It can be caused by sleep arousal difficulties, polyuria, and/or bladder dysfunction.

What are the myths around bedwetting?

- Child bedwetting is caused by drinking too much before bedtime.
- That the child has deep-seated psychological problems.
- That the child is too lazy to get out of bed to avoid it.

My personal experience

My personal experience of primary enuresis didn't have a positive beginning. When I was experiencing my condition people assumed that it was because of my home life, but really their opinions were unconscious bias.

I found out that my diagnosis was all down to genetics. My mother, uncle and grandfather had all had my condition and it had resolved for them around the age of twenty.

My family had discussions with me about the support and guidance available to me. They explained that in the country they grew up in, there was no support available on how to manage and it was very difficult.

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How do I manage my condition?

I manage my condition with bladder training, medication, enuresis alarm, bladder diary and night time diary. Though everyone with primary enuresis is different and different things may help them.

How does it affect my everyday life?

When I was younger it affected emotional and social wellbeing because I did not understand my body and what was happening. I felt different from other children and my friends. I avoided social activities, such as sleepovers or school trips.

There is a real need for better support from health professionals and teachers. There is a real lack of education and specialist support in school which creates real challenges for young people to be able to share what is going on for them and the help they need.

I didn't ever want to disclose my continence problems at school to either friends or teachers because I was worried about the stigma, bullying and social isolation.

Sadly I still feel guilt, shame, humiliation and have lost my self-esteem. Sometimes I feel quite helpless and hopeless.

What support do you wish young people with primary enuresis had?

- An inclusive toilet and improved toilet standards in schools which young people have unrestricted access to throughout the day.
- Specialist professionals who can speak about the challenges faced by young people with continence problems. This could help to remove the barriers to successful self-management of their symptoms.
- Better specialist education for teachers, pastoral support and other educational staff so that young people can get the support and advice they need.
- Increased support at school to enable young people with continence problems to achieve their academic potential.

What advice would you give to other young people with primary enuresis?

Be yourself and speak to family and trusted adults. Also, networking with others who share similar experiences can be really helpful.

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