

EXTERNALLY LED PATIENT-FOCUSED DRUG DEVELOPMENT MEETING

31 OCTOBER 2023

PRESENTATION

Living with hEDS including GI issues

SPEAKER

Mr Harry Radcliffe



No Disclosures



Introduction

Harry Radcliffe

Instagram: harrythezebra1

- 38 years old
- First diagnosed with EDS age 17 after numerous dislocations during contact sports
- When I was 30 years old, deterioration began
- Since 2015 I have faced multiple challenges
- Have a carer who comes throughout the day



What Symptoms Do I have:

1. Gastro and Intestinal Issues resulting in consistent vomiting.
 - Very slow digestive system from oesophagus downwards.
 - Slow oesophagus, gastroparesis, slow duodenum – small intestine – colorectal
 - Bile reflux
2. Colorectal Issues
3. Joint subluxations
4. Chronic Pain
5. Bladder and prostate issues
6. FND – Functional neurological disorders
 - Cognitive ability
 - Memory
 - Spasmodic episodes

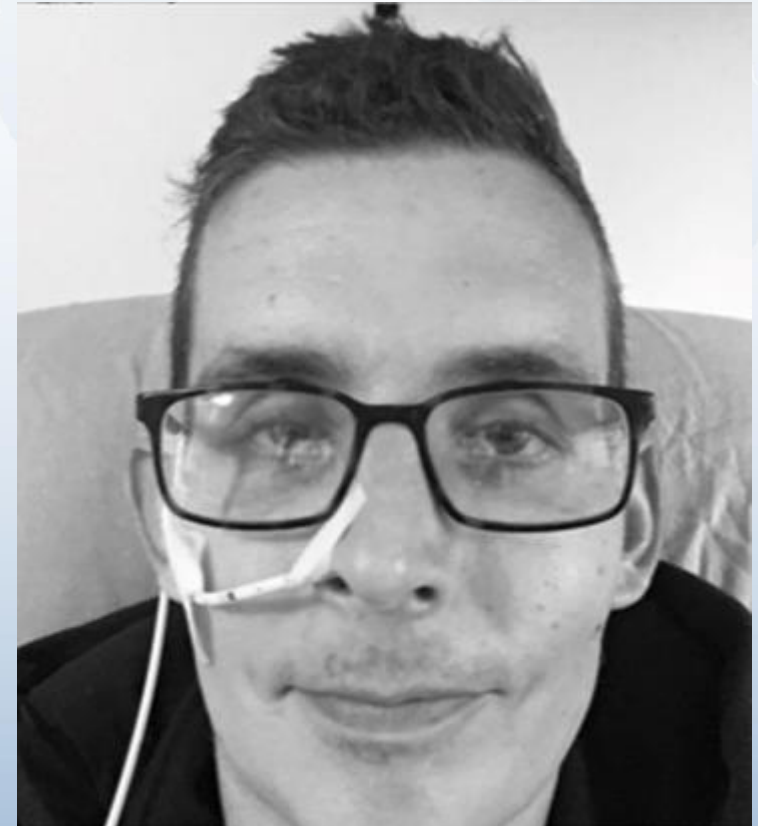


How Do Each of Them Affect Me?



Gastro and Intestinal Issues (Part One)

- Lost 5.5 stone (35kg) due to inability to keep food and supplement drinks down
- I would vomit multiple times of days
- Dehydration and hospital admissions
- Nausea
- I still vomit daily



How Do Each of Them Affect Me?

Gastro and Intestinal Issues (Part Two)

- Anxiety
- Constant fear of weight loss and setbacks
- Malnourishment – loss of hair, sores across body
- Mental Health challenges including depression



How Do Each of Them Affect Me?

Challenges with Treatment

- I vomited supplement drinks daily.
- NG Tube – vomited feed up daily and tube weekly.
- NJ Tube – 2.5 years, consistent daily vomiting.
 - Vomited tube up at least monthly.
 - Lost just below a further stone in weight.
- We are now trying partially predigested drinks with mixed but more positive results.
 - Vomit at least one drink daily.
 - At least 2 days per week all drinks will come up.
 - However, I am putting weight on slowly with instability.



How Do Each of Them Affect Me?

Colorectal Issues

- Severe constipation and severe pain.

Treatment to Date

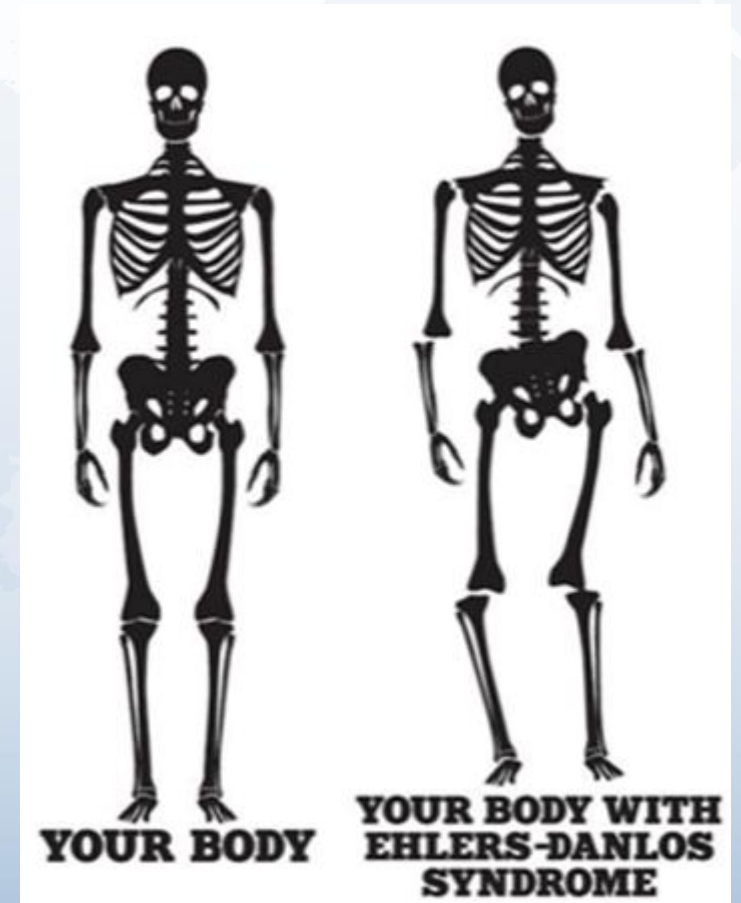
- Peristeen
- Medication



How Do Each of Them Affect Me?

Subluxations

- Multiple weekly subluxations of key joints.
- These include my hips, knees, shoulders, shoulder blades and fingers.
- Hips, falls, concussions, secondary injuries
- General mobility – Require a mobility scooter in and outside of the home
- Numerous hospital visits due to pain of subluxations or concussion.



How Do Each of Them Affect Me?

Treatment Methods

- Tools around the house including stairlift and a hoist
- Physiotherapy
- Rheumatology
- Orthopaedics
- Medication

The above do very little, my joints have continued to deteriorate.



How Do Each of Them Affect Me?



Chronic Pain

- Pain is totally debilitating. Stops me from sleeping, resting, being able to be on my mobility scooter.
- Pain is normally the result of subluxations but can also be attributed to significant flare ups of random joints.
- Hips receive the bulk of it, which in turn flares up prostate, bladder and anything else near.
 - multiple ambulances and hospital visits which have unsuccessfully treated the pain.

Treatment Attempts

- Have seen two pain management consultants as well as specialists in rheumatology and orthopaedics.
- Medication, have explored all avenues of medication outside of opioids. Then moved to opioids which include IV morphine, oramorph, fentanyl, oxycodone and ketamine & lidocaine infusions.

How Do Each of Them Affect Me?

Bladder and Prostate Issues

- Urine retention. Severe pain.
- Leaks through urethra – agony both in urethra and bladder.
- Consistent infections.
- Chronic prostatitis

Treatment Methods

- Catheter – urethral then suprapubic – complications.
- Medication





How Do Each of Them Affect Me?

FND - Functional neurological disorders

- Cognitive ability – struggles with verbal communication and reading
- Memory and retaining information
- Spasmodic episodes
- Overwhelmed in busy places or large crowds

Treatment Methods

- Medication

Mental Health



How EDS affects my mental health

- Loss of self-esteem, of self-image, self-confidence and how friends view me.
- Lack of motivation.
- Daily high anxiety about my symptoms.
- Fear of being a burden on my wife and how I have changed her life.
- Fear that this is my life and it will never change – I could get worse.



Mental Health

Treatment Methods

- Taking antidepressants.
- Try to keep a positive mental attitude.
- Have grown my own EDS support network online, predominantly through Instagram.
- Have tried therapy, however the therapy offered in my county does not provide any specialist in chronic illness, or even just health psychology. They generally use the least qualified therapists or counsellors.
- My wife, family and dog.



Frustrations

- No stability in any of my symptoms.
- Great change in my day-to-day life as well as expectations for the future.
- Lack of mental and emotional support for rare illnesses
 - Support groups offer little actual help in my experience
- Lack of understanding amongst wider population.





**Thank you for
your attention**