

Creating a culture for work integration

SEDSConnective

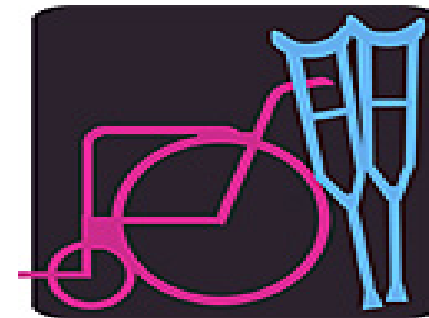
Symptomatic hypermobility EDS HSD

Neurodivergent Charity

- Jane Green MBE
 - FCCT Founding Fellow of Chartered College of Teaching, NonExec.Board NED
 - MA Ed.
 - Advanced.Dip.Education.(Child Development),
 - PGCE QTS,
 - BSc (HONS) Psych.
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- X witter @JGjanegreen @SEDSConnective
 - Website: www.sedsconnective.org
 - Linkedin: <https://bit.ly/2UZ9uC9>



My story-parent, carer, disabled, professional and charity lead

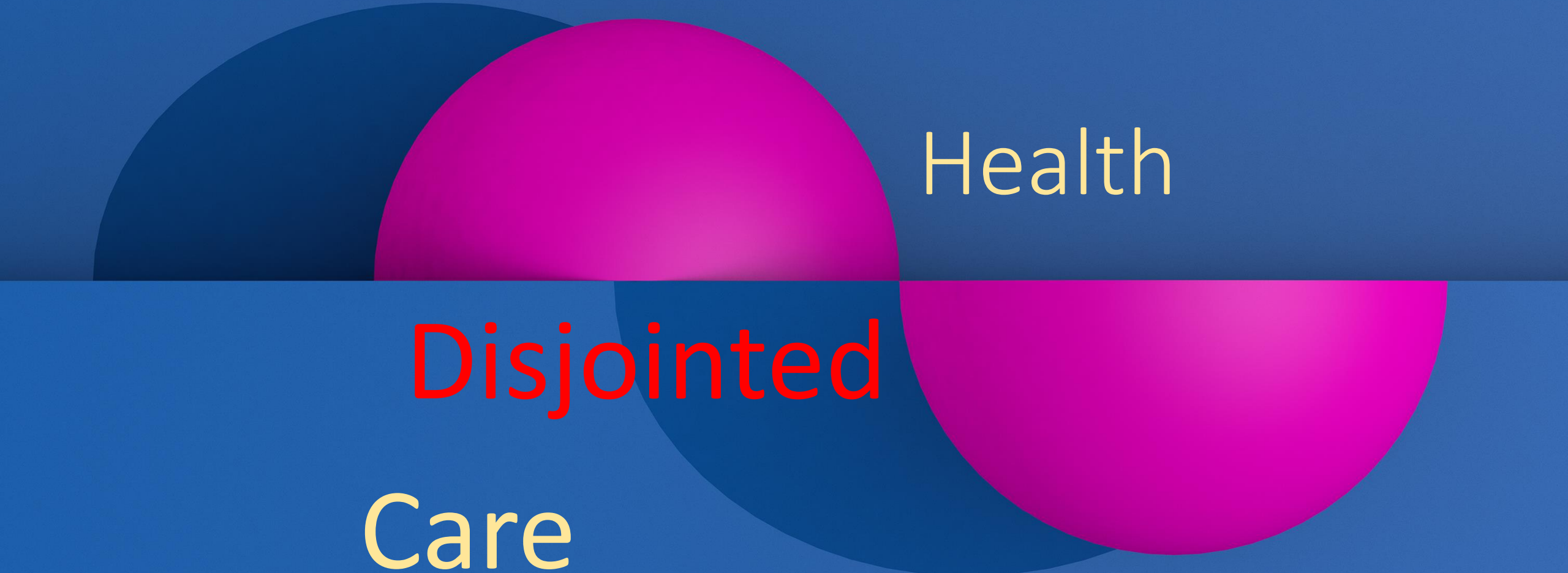


Neurodivergence

Health

Disjointed

Care





Why is this important?

There is no cure for symptomatic hypermobility or if diagnosed EDS HSD JH pgHSD pgJH, but individuals can be supported to regain some quality of life and support from the trauma of symptomatic disbelief and being diagnostically overshadowed. It is heritable and generational

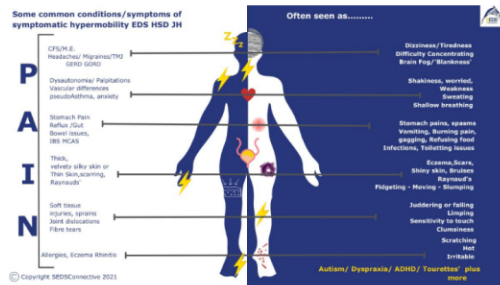
In 2018 I started a small, voluntary community group actively funding when possible and advocating in the areas above. It started in 3 villages but soon grew now with global reach into charity punching above it's weight. Winning awards Covid, helping save lives



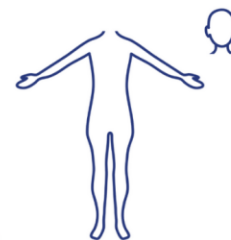
I left school early, considered dim and a hypochondriac. I was often unexplainably unwell and injured but learnt to hide, MASK my pain and injuries. I self studied very late, degrees and national/international career helping students but knew there was something missing in our training and research. Eventually I lost my career due to stereotypical historical bias. I received 2 diagnoses age 53/54 and recently another one, but no support. I knew there would be others like me but could not find what needed to be done.



Why and How ?



Brain AND Body



"I am more than my disability but SEDSConnective provides me with a community that believes me about my conditions, educates me, and most importantly socially accepts me and my family to grow" Member

What have been the challenges?

SEDSConnective have had to take risks and be innovative in unrecognised and protective arenas of health, social care, education plus. No prior joining up. Ill/disabled voluntary community user led and many also sandwich carers. Standard ways of thinking/working from the past predominant. The pressures to secure funding have been extremely difficult with no formal connections or assets

What have been the benefits?

- Integrating health, care and education. Helping to save lives, being believed, valued
- Empowering the most disenfranchised by health, society, employment, life, generational
- Active specialised support for members not available elsewhere, by us for us
- User led community voice with expertise leading in equal power
- Building partnerships and connections

What does the future hold?

SEDSconnective will continue to: Actively support members to live more fulfilled lives for their own health and dependents. Transform the health, care education landscape for neurodivergent individuals and allied professionals. Continue to grow in this groundbreaking area linking up body and head issues, leading research community partnerships, securing more funding for equality equity, diversity & inclusion in health, education, care, employment and all aspects of society.



**Can we unify and connect the dots?
Health is a concept is as equality and
equity. The models are incomplete and
needs a balancing, UNIFYING new model
or theory**

Social



Medical

BioPsychoSocial

**'We are more than processes
and systems'**

Diversity or divergence ?

An Ecumenical Matter

Stigma or Stigmatising ?

“If you can’t connect the issues, think Connective tissues”

- Jane Green
- MBE For services to neurodivergent people and those with related joint hypermobility conditions including Ehlers-Danlos syndromes 2022

Email: general@sedsconnective.org

Public Facebook Page: <https://www.facebook.com/SEDSconnective>

Instagram: [@sedsconnective](https://www.instagram.com/sedsconnective/) | <https://www.instagram.com/sedsconnective/>

LinkedIn: <https://www.linkedin.com/company/68181150/>

YouTube: <https://www.youtube.com/channel/UCHzgTdMyUTXvx8EISV4ZcYg>

Linktr.ee: <https://linktr.ee/Sedsconnective>

X (witter) @JGjanegreen @SEDSConnective

Website: www.sedsconnective.org

Linkedin: <https://bit.ly/2UZ9uC9>

