

# Sarah White

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volunteer and parent



# Hopes

Share my experience of working with young people in the Community Pain and ME/CFS service

Discuss how and why we have developed a pathway to support young People and how it's going

Share my volunteer work – in Camhs P2P peer support service

Personal experience and future hopes

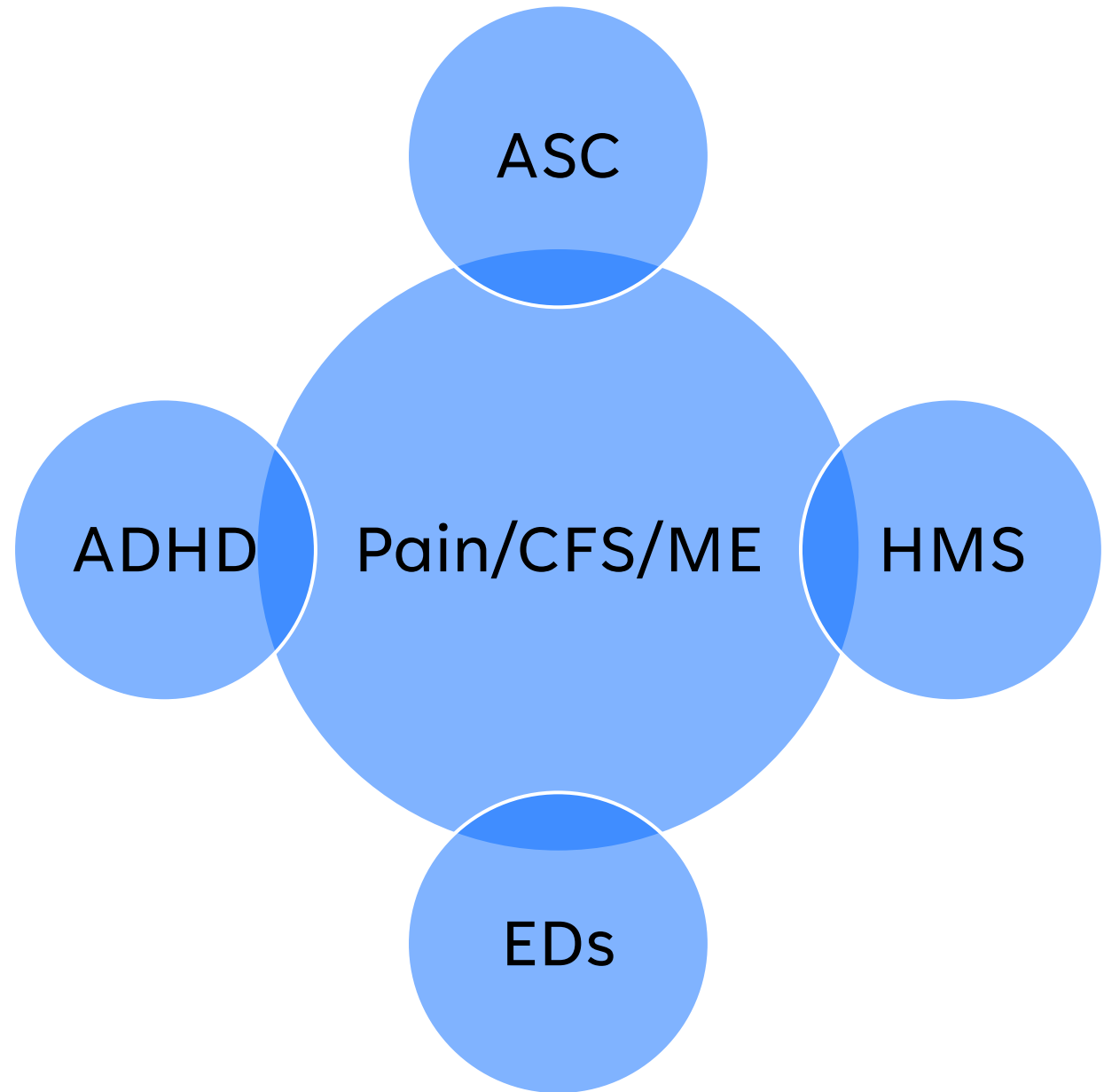


## Links and overlap seen in Pain CFS/ME services

Connective tissue disorders –  
hypermobility, EDS – (Eccles)

Neurodivergence ASC/ ADHD/  
Dyspraxia

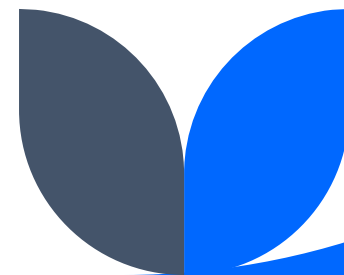
Eating disorders – 4- 23% people  
with ED are Autistic



# Links with neurodivergence and Chronic pain and Fatigue

Dr J. Eccles – Brighton and Sussex- Research highlights a strong link between (ASC) and chronic pain, driven by high rates of co-occurring joint hypermobility and autonomic dysfunction.

Over 50% of autistic individuals show elevated hypermobility, causing increased pain and fatigue. Her work connects joint flexibility, pain, and anxiety, impacting mental and physical health



# Background to developing the young person's service

- In 2022 awarded funding from AHSN patient public involvement
- Support underrepresented group (young people with pain and or fatigue)
- Referrals 16 – 26 increasing ++
- Focus group





# Focus group recommendations

Need for peer support

Pain/fatigue management programme for YP

Tailored approach factoring in needs

Communication methods



# Designing the service

1:1 Ax and prep for group

The Group ages 16-26

Group approach DNA-V

Led by 2 staff both Physio's with psychological MFN and DNA-V training

Implementation of group

6 weeks 2.5hrs virtual group with final week F2F at the Broadway Cinema



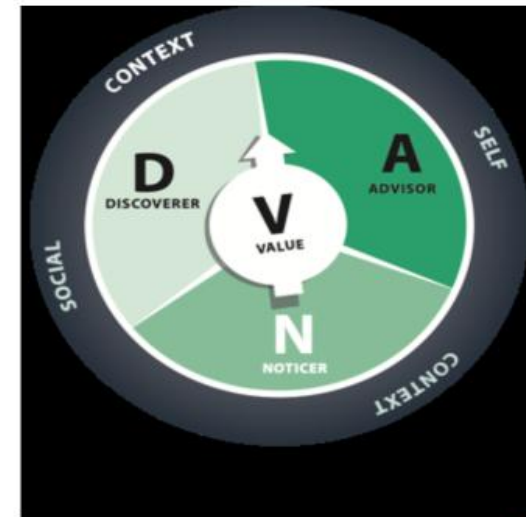
# Designing group

Group based PMPs well established

Majority using contextual models  
ACT/MFN based

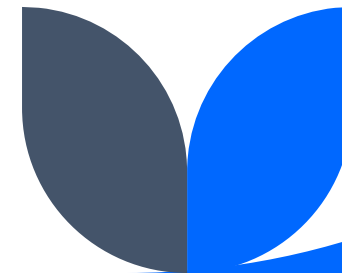
Included standard pain/fatigue  
management skills/ education

Using DNA-V framework with focus on  
sensory soothing and value-based  
action



[picsnhs.org.uk](http://picsnhs.org.uk)  
[@pics\\_primary](https://twitter.com/pics_primary)

Primary Integrated  
Community Services Ltd 



# Reflections



All participants reported being part of the group and working with people a similar age was useful

“ I felt understood”,

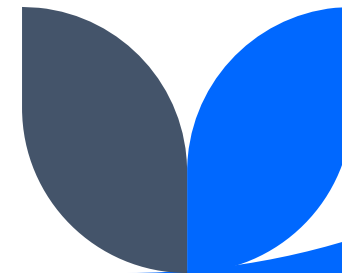
“they all understand age challenges”

“ it was helpful to hear how other people are coping with pain and fatigue”

“ we all have similar problems and worries”

“ having a routine every week and something to aim for”

“ I think it helps so much to meet people my age and feel not as different and alone”



# Feedback

“I’ve learnt that it is ok to feel the way I am and how to deal with it.”

“I’ve made some friends my age that actually understand what I’m going through”

“Felt like I’m understood”

“Given strategies to help manage pain”

“Given me tools to help”

“Useful solutions to maintain a helpful sleeping plan”

“Met other people with similar issues. I don’t feel alone”

“ I learned new ways to minimise pain”

“ made a good friend”

“ Able to understand pain and fatigue”

“Meeting new people in the same position “

“Meet other people who understand”

“ know more about the things that help me manage pain”

# What is working

- Reporting improved outcomes in MH and value based activity
- Improved self care and self compassion, sensory awareness
- Ability to ask, advocate and take steps towards values
- We assist with education/ work and direct to employment support, SP and the charities.
- Communication
- Connections and support with peers
- Sharing ideas – creativity!
- Living a life with purpose and meaning despite ongoing health challenges
- We offer ongoing support – refresher sessions

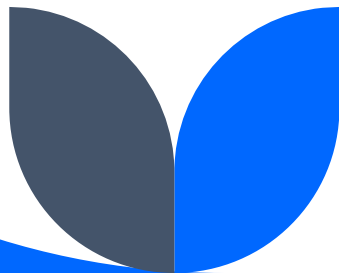
# My reflections

- Our Young people are highly resilient
- Environment and attitudes of the service provider matter
- Creativity and ideas on how to support themselves and each other
- They want to improve and engage
- They are self aware and honest and open
- They learn quickly and can apply

# Camhs Eating Disorder service – Parent 2 Parent support



- How I came be involved
- Links with neurodivergence
- What we do, how we support
- Groups
- 1:1 support for the family
- What's going well
- Improvements





# Thank you

Any Questions?