

Experiences of PTSD and ADHD support on Wirral

The purpose of this short report is to provide a unique snapshot of insight into how people who access Sole Survivor PTSD Support CIC Peer Support Groups feel around access to services, quality of care and treatment in relation to Post Traumatic Stress Disorder (PTSD) & Attention Deficit Hyperactivity Disorder (ADHD); Through sharing real lived experiences, perspectives and perceived barriers to clinical support.

Healthwatch Wirral (HWW) works to ensure that local provision is the best it can be from the entering and viewing of health and social care premises, to engaging with the public and professionals and carrying out research to providing independent qualitative evaluations. It's our job to listen to people's experiences and share their views with those who can do something about them.

Our job at Healthwatch is simple, we are here to help make health and social care work better for everyone. Healthwatch is independent and designed to give local people a voice to help them get the best out of their local health and social care services.

Whether it's improving them today or helping to shape them for tomorrow. Local Healthwatch is all about helping people to share their experiences to help influence the delivery and design of local services. Healthwatch Wirral brings unique value, due to our unbiased independence.



The 'Foundations of Quality Improvement' must have what people tell us about their treatment and care at the heart of all we plan and do. We must be able to show that our actions and decisions reflect people's views. We must ensure that everyone is respected, involved, valued and confident that we are giving and receiving quality care.

Background

Healthwatch Wirral were contacted by local organisation Sole Survivor PTSD Support CIC for advice regarding around the route to accessing a formal diagnosis for PTSD from General Practice.

There was an initial focus group titled "Issues to Getting a PTSD Diagnosis" held at the Birkenhead Peer Support Meeting, which was attended by 15 clients where the question was put to them.

Most of the clients across the geographical area that Sole Survivor conduct their Peer Support Groups were having difficulty attaining referrals for assessments for PTSD, and were often prescribed medication for depression and anxiety, while the root cause of the issue, which in most cases was undiagnosed trauma, was left untreated.

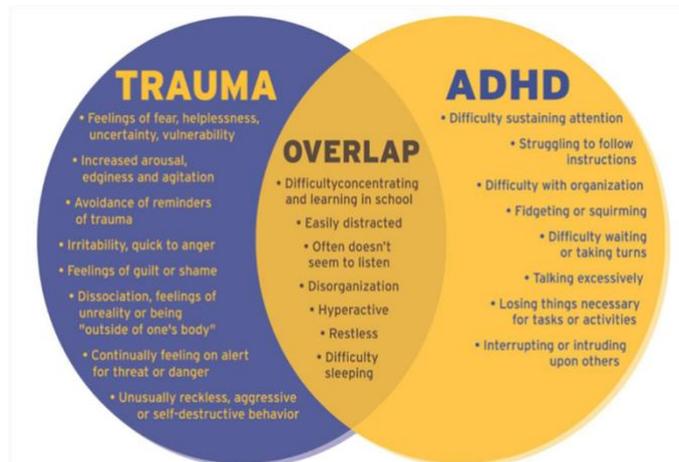
Members of the Support Group expressed that there was a feeling that the only option being offered presently from General Practice was a referral or to self-refer through to Talking Together Wirral for general CBT based counselling, if that was offered at all.



Why talk about ADHD & PTSD together?

There are different perspectives when it comes to Attention Deficit Hyperactivity Disorder (ADHD) and Post-Traumatic Stress Disorder (PTSD). While some clinicians argue that we are over diagnosing trauma as ADHD, others argue we are over-diagnosing PTSD and missing the ADHD. Complicating matters, PTSD and ADHD commonly occur together.

ADHD makes a person more vulnerable to developing PTSD after a traumatic event and can intensify PTSD symptoms. And trauma may activate ADHD in those genetically predisposed to it.



Source- <https://www.childdevelopmentclinic.com.au/adhd-and-complex-trauma.html>

About Sole Survivor

Sole Survivor PTSD Support CIC was set up in 2019 with the help of a small grant and support from Involve Northwest's Community Spark Fund.

Since then, Sole Survivor have facilitated weekly trauma-informed Peer Support Groups in the community. The organisation currently runs an online group, and three free-to-attend, face-to-face groups in Birkenhead, New Brighton and Liverpool City Centre.

There is also an adult ADHD Drop In, which combines a social group, art therapy and weekly health MOTs for the clients at partner organisation Wirral MIND's building on Chester Rd.

Sole Survivor are contracted to provide PTSD Keywork support to the DWP via their work readiness programmes across the region and are also contracted to supply PTSD Life Coaching and focussed key work to homeless support charity Wirral Ark at Mary Cole House, which is their homeless accommodation Hub and Wirral Ark's clients who live in the community in supported accommodation.

Sole Survivor have recently completed the first CWP commissioned project with partner Share Aid in Chester; Sole Survivor supplied a Mental Health Drop In for the Cities homeless at Share Aids homeless hub and 1:2:1 Mental Health Life Coaching for those clients who were temporarily housed by Local Authority CWaC whilst waiting for long-term accommodation.

Alongside this activity the organisation offers ADHD Life Coaching, Trauma Informed modalities of therapy and CPD accredited PTSD awareness training.

On average Sole Survivor will see and speak to 60-80 people a week who are living with the effects of trauma.

<https://ptsdsupport.co.uk/>

Approach

Healthwatch Wirral & Sole Survivor Lead, Matt Shepley arranged a second focus group with Sole Survivor members. We also offered a variety of ways for members to share their views & lived experiences and any suggestions around how services and communications could be improved. Information was provided to Healthwatch Wirral outside of the focus group.



PTSD

Healthwatch were sent information related to "Issues with Getting A PTSD Diagnosis" and this was followed up further during the focus group in September 2023.

The experiences were varied, and it was evident that there were many inconsistencies in the client's referral process, diagnosis, treatment, and care.

Whilst some of the cohort received help, usually in the form of CBT Counselling, the general feel was a lack of confidence that the type of counselling available was appropriate, as there was no offer of any other therapy i.e. EMDR, Trauma Informed CBT etc..

There was a sense from most group members that they felt 'fobbed off' by their GP as they were often prescribed medication for depression or anxiety and conversations around follow on referrals often did not take place.

Other comments received were that:

- People felt like they had to be suicidal before accessing any help'
- One client was fearful of telling GP or any other health professional in case she was deemed unfit to look after her children.

Experiences



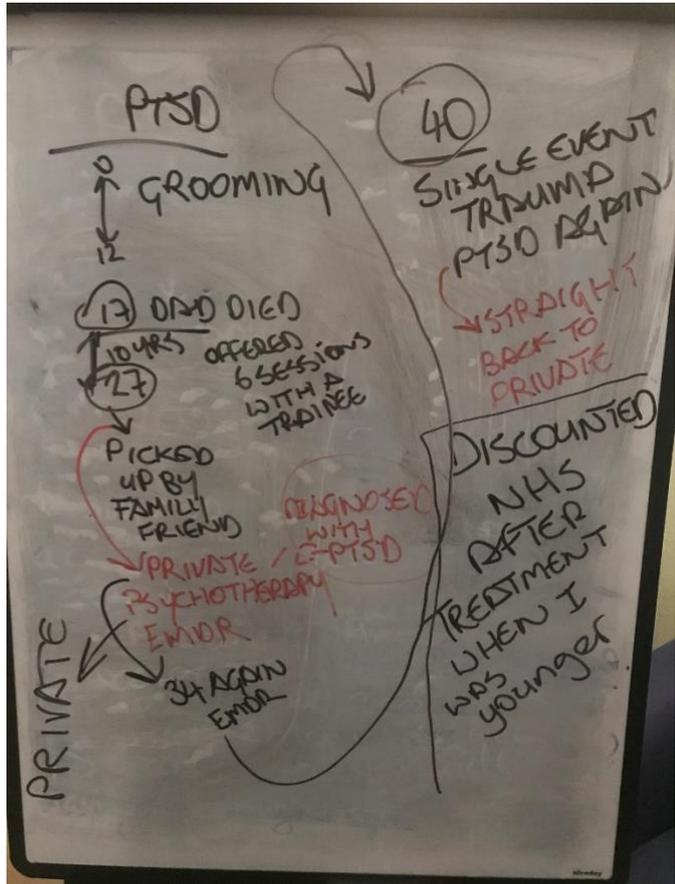
I was referred to Sole Survivor via a Social Prescriber after my GP refused to help. I was supported to go back to GP and then got help.

I spoke to GP, received assistance from Talking Together Wirral for anxiety and depression, but didn't feel it addressed the presenting trauma issues.

I visited GP, no support, my family has private healthcare, so I was lucky and could access support from private Psychiatry.

My GP advised that what I was experiencing could be PTSD, but then made no referral.

I was referred to Involve Northwest by GP, received help from Maggie's Cancer Care, but no referral to Secondary Mental Health, I felt "fobbed off".



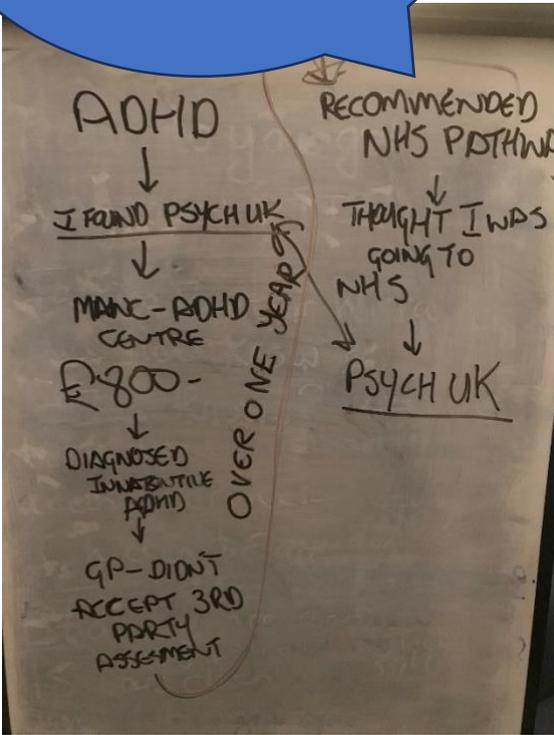
ADHD

Clients accessing the adult ADHD group have expressed that there are real issues around waiting times. The group shared that they are being told it's a five to ten year wait for a diagnosis. Sole Survivor have been active in supporting clients to know about the "Right to Choose" paperwork.

Some group members have advised that when they have taken the self-assessments to the GP's they were questioned why they would now want a diagnosis. A couple of members advised that they had been told that their referral had been lost, so would have to start from 'scratch'.

"My GP said, 'what's the point of you getting a diagnosis this late in life, you have coped well so far'"

Journey Shared by group participant.



Appointments, procedures, and hospital admissions

Many shared that if they are at medical appointments for other health concerns or treatment, there can be real difficulties in how they are communicated with by health professionals, and this can have an adverse effect on how they are treated as they may often react in a defensive manner.

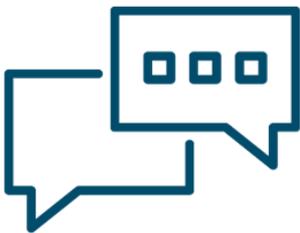
This was also shared by those within the group who did have a formal Neuro diversity diagnosis and/or diagnosis of PTSD.

It was shared that often, there is nothing on their notes or medical records or that they feel this has not been looked at or considered when offering them treatment.

Despite increasing prevalence and cost to the health service, the group talked of neuro diversity and PTSD not seeming to be a high priority for the NHS.

Feeling stigmatised was a clear trend. Added to this the view that the NHS treats their minds and bodies separately and do not take the whole person into consideration.

If I had broken my leg, how I was treated for this would be straight forward, unless my Mental Health at the time was bad or I was getting overwhelmed. But, I don't think I would be asked about anything else about my other conditions' .



'When I was in hospital for an operation, I had to stay on a busy ward. This really triggered my PTSD. I did become agitated, and I suppose confrontational.

I tried to explain why I was struggling but didn't feel understood. I was told that there was nothing on my file around my PTSD but there was a record of my history of using substances.

I have been clean for 15 years now and I felt so angry that this was all they were looking at and probably judging me. I was worried about this effecting how I was treated & I asked if this could be taken off. I was not given an answer, I felt fobbed off.'

Parity Of Esteem. Examples were offered around situations at appointments for physical health conditions or in hospital. Generally suggesting that existing diagnosis or MH challenges were not being taken into consideration when planning and providing care and treatment.

The group talked about barriers to getting the most out of the GP's appointments as they can be so overwhelming. People referred to struggling to articulate clearly the issues they are facing, what they want help with and how they are feeling. It was common that appointments become a big deal,

often being built up so much mentally, that by the time they get there they don't know what to do and anxiety can take over.

The amount of time and pressure to get everything covered was a perceived barrier. Reference to getting confused by ambiguous or superficial questions, clinical language and not quite understanding what is being asked of them and why.

When reflecting on Person Centred Care, the importance for staff to remember that executive functioning is a challenge for the client was stressed and that health professionals regularly misunderstand this.



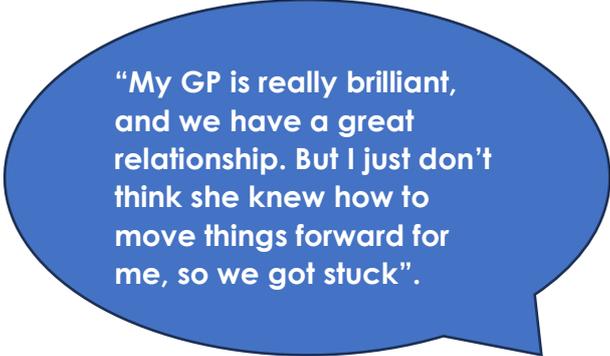
"I wasn't given enough time, felt rushed, which made me clam up and get angry".



"I was given so much information. By the time I walked out I had no clue what we had agreed and what happens next".

Discussions were had around the inconsistencies in the knowledge of medical staff around ADHD and PTSD. It appeared that when experiencing a clinical or professional with good knowledge and an empathetic approach, the interactions were always more positive, leading to more confidence and better engagement. Some members suggested the need for ACES (Adverse Childhood Experiences) and Trauma training for staff as a standard.

It was reassuring that some of the respondents has a good relationship with their GP. However, several felt like the GP didn't know how to move things forward for them, so still felt stuck.



"My GP is really brilliant, and we have a great relationship. But I just don't think she knew how to move things forward for me, so we got stuck".

A few people identified that there is a certain trust that they naturally have in what professionals say and indicated that it can create a power imbalance, so even if they don't agree, they tend to people please and not speak up. Reporting that they would be less likely to challenge a

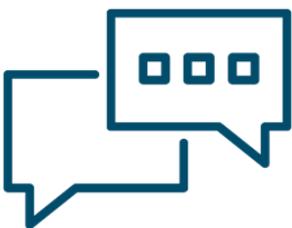
decision, ask for more clarity or understand what had been said. Others described feeling like they had to exaggerate their situation or be in crisis to get any outcome.

The group talked about the benefits that a **health passport** may bring that could be taken to hospital and health appointments. Many had never heard of a health passport but thought it would make a difference having one.

The group generally felt a health passport would help people treating them to understand how best to support them. Especially if they were in pain and/or in situations that heighten anxiety or stress.

Consensus was that it would help all round to make certain that important information was communicated about needs to doctors, nurses and other healthcare staff, without having to retraumatise them by having to validate themselves by telling their trauma story over and over again to be understood.

Waiting Lists and communications



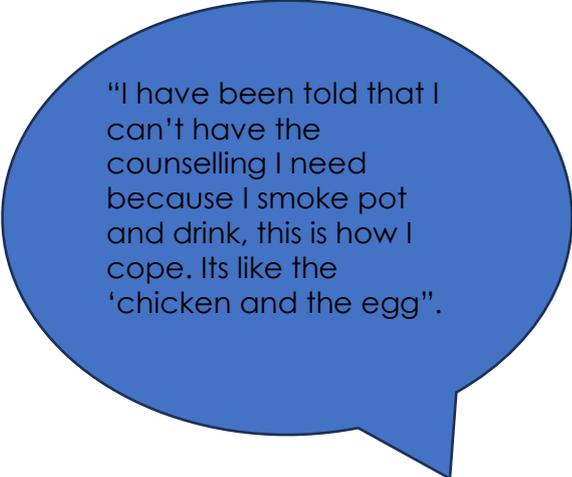
"I was told by my GP that I had been referred for an assessment but not given any indication of what that meant. But at last it felt like I was on my way to getting my life sorted and feeling understood.

Unfortunately, I had no contact from that point. I felt just left, there was no communication for 12 months. I called my GP and asked what was happening and they couldn't tell me. The GP who had made the referral was no longer there, so had to go through explaining myself all over again. Which I find so difficult to do.

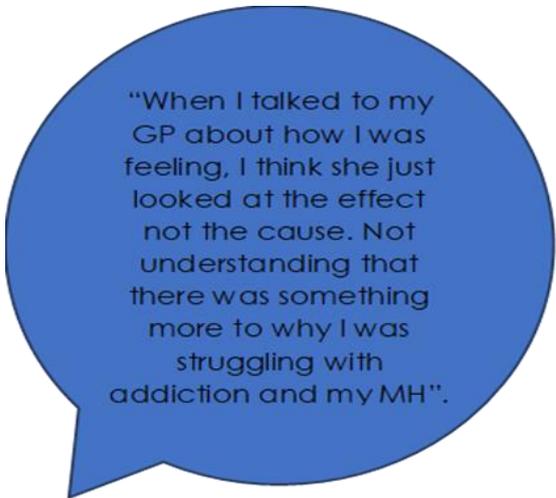
I felt invisible and left adrift. I am still waiting in Limbo".

People reported feeling that they are on the wrong pathway for support. One member repeatedly stressed the struggle for validation and diagnosis of PTSD from the NHS that they were facing. Some group members spoke of being referred to support in the form of Social Prescribers, Community Connectors and other community-based support. The feedback on this support was good and people spoke of the relief to know that they could reach out to speak to someone and be listened too.

The practical and social support was also described as beneficial. With people getting help with other areas (cost of living, housing, debt, drug and alcohol services). However, it was expressed that this should only be in addition to & not instead of the right clinical & appropriate therapeutic interventions which were lacking, hence the reliance on the third sector for support.



"I have been told that I can't have the counselling I need because I smoke pot and drink, this is how I cope. Its like the 'chicken and the egg".



"When I talked to my GP about how I was feeling, I think she just looked at the effect not the cause. Not understanding that there was something more to why I was struggling with addiction and my MH".

Participants in the session suggested that the 'go to' often being anti-depressants, anxiety medication and others, which could at times lead to them being over medicated and/or having negative side effects.

All respondents said that they find it difficult to self-regulate, monitor medication and their general health independently.

A point was raised around medication reviews needing to be regular. Some disclosed that they had not had medication reviewed at all.

The group said that between them they had no idea of what the pathways for a referral to secondary mental health was. From there, also what the process and possible outcomes there are.

December 2023- ADHD Medication Shortages

Healthwatch Wirral have been contacted by residents and organisations in relation to the impact this is having here on Wirral.

Subsequently Healthwatch revisited communication with Sole Survivor PTSD Support CIC to understand more about people's experiences and the challenges. See Link to article for further information and guidance.

<https://healthwatchwirral.co.uk/adhd-medication-shortages-in-wirral/>

Healthwatch Wirral would like to thank all who participated and contributed to this snapshot report. With particular thanks to Matt Shepley, Founder and Director of Sole Survivor.

This report will be published and available on the Healthwatch Wirral Website. It will also be shared and referenced through our work with Healthwatch England, commissioners, key decision makers and providers of relevant health and social care services.



Useful information

CWP Adult ADHD Team 0300 303 3157

Wirral CAMHs 0300 303 3157

Specialist ADHD Service Contact Information and Patient Advice Line and a range of helpful short videos can be found on the CANDDID website:

<https://www.canddid.nhs.uk/adhd>

The following support services and resources may be useful:

If your mental or emotional state quickly gets worse or deteriorates, this can be called a 'mental health crisis'.

CWP Crisis line is available 24 hours a day, 7 days a week and open to all ages:

0800 145 6485

ADHD Foundation <https://adhdfoundation.org.uk/>

The National Attention Deficit Disorder Information and Support Service

<http://www.addiss.co.uk/>

www.adhdandyou.co.uk

ADD/ADHD Information Online www.adders.org.uk

You can tell us about your experiences around ADHD services & Support or any NHS and social care services by visiting our Feedback Centre.

It only takes a few minutes to tell us about your experience of health and social care. We use your views to tell the people that plan and provide these services what you think. We raise any concerns that you tell us about with the people running both NHS and social care services to help make care better.

<https://speakout.healthwatchwirral.co.uk/>