



Self Assessment of our SEND Implementation

June 19

*A new approach to special educational
needs and disability*



Development of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) workshop for young people

What was the issue

- Not enough capacity to see all the referrals for CFS/ME individually
- Young people with CFS/ME consistently identifying that they struggle with social isolation and explaining their condition to friends/school

Our Journey so far

- Developed an assessment proforma for young people with CFS/ME
- Working with the adult CFS/ME team and sharing resources
- Development of a workbook and education resource for young people with CFS/ME
- Referrals gradually increasing each year for young people with CFS/ME making 1:1 work more challenging and leading to longer waits
- Identifying that by seeing these young people in a group setting we could be more effective with capacity plus it would give them the opportunity to meet other people with the same problem and may help tackle some of the elements of social isolation
- We ran our first workshop consisting of 3 sessions in February 2018 where we had 50% attendance but positive feedback from those that did attend. However, the 50% that did attend all needed further 1:1 follow up appointments
- We made some alterations to the format and the next group ran in October 2018 and had 60% attendance but half of these needed 1:1 follow up after the group
- In March 2019 we kept the same format and had 20% attendance rate (1 child). They did not need any further follow up after the 3 workshop sessions. It was felt that this was due to the resources used and also the opportunity to have some 1:1 time as part of it

What have we done?

- Changed the format a final time so the workshop now includes 3 group sessions and 3 individual sessions (runs over a 6 week period) with a follow up group session 3 months after completion of the workshop.
- We have just run the 6 week workshop in this final format and had 80% attendance, very positive feedback and every young person has come out with 2-3 SMART goals that they are working towards during the break between the workshop and the review session.
- Accessed psychological skills training to help support the rehab process, especially important as Clinical Psychology will no longer accept referrals for young people with CFS/ME

What difference has this made?

- Young people are meeting others in the same situation as them. They have found it reassuring that they are not the only ones going through this and a lot of the frustrations are shared amongst all of them

- Young people and their families are learning how to manage the condition themselves and not rely on therapist to give them solutions
- Young people had the opportunity to share experiences and this was particularly evident around how different schools support students differently which has helped families to have conversations with school and learn about different options available or support services e.g. SENDIAS
- Less young people with CFS/ME staying open to the physiotherapy caseload as they are learning to self-manage

Areas for further action

- The issue of how schools are supporting young people with CFS/ME was a predominant theme of the last group. We need to do more work around educating schools. We have previously run a school training day but this was several years ago and I think we need to re-visit this
- The lack of specific psychology support is an issue for these young people. As physiotherapists within CFS/ME we need to learn more psychological strategies within our scope of practice to be able to provide early intervention in this area and help identify when onward referral to CAMHS is appropriate

Immediate next steps

- Organise further schools training and resources around CFS/ME

Author

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