

Walking With You Parent Support Group (Oxfordshire) Newsletter 19

WWY in September

This was an open session to share concerns that parents are facing Over the coming months

Transgender

- A parent shared her concerns about managing her child's expectations going into Yr 11 around social transition and changing their pronouns. Plans have been put in place with school to adopt their chosen name.
- During the summer holidays they wanted to be known using their chosen name.
- School and the family have been really supportive but Mum was feeling overwhelmed by what her son expected and not knowing what to expect in the future.
- It was a real shock to hear that their child wanted to change their name.

Attitudes towards gender transitioning have changed a lot in a small space of time. Many young people are expressing that they want to change their name and schools are generally being very accepting and supportive.

It is a big thing to tell someone that you want to change your name. Many young people struggle with this but it can be a huge relief for them when given the space to talk about how they feel and what they would like to do.

Not all young people who question their gender will want to follow through with physical transition.

It is important to acknowledge that parents may need to work through the grief process as part of accepting their child's transition. Parents may need a lot of support when adjusting the change.

Experience shared by a Parent Volunteer:

- Supporting a young person through Gender transitioning can be a long journey with some difficult challenges to work through.
 Choosing to use a different name can be difficult for families to accept.
- Parents need a period of adjustment. Different family members may find the transition more difficult to accept and need a longer period of adjustment. Grandparents would definitely have struggled with the change of name.
- Initially mum (Parent Volunteer) was against the idea of their child's gender transition. However, having seen the positive impact that the transition has had on their son's well being, they are now the biggest supporter.

Useful Organisations and resources.

Oxfordshire CAMHS

https://oxfordhealth.nhs.uk/cam hs/oxon

Links to previous newlstters
Participation in Oxfordshire |
Oxford Health CAMHSOxford
Health CAMHS

Oxfordshire Parent Carer Forum

https://oxpcf.org.uk

Autism Family Support

www.afso.org.uk Autism Oxford

<u>Homepage - Autism Oxford UK</u> <u>Limited</u>

Oxfordshire Youth www.oxfordshireyouth.org

Oxfordshire Mind www.oxmindguide.org.uk

Be Free Young Carers

https://befreevc.org.uk

Understanding the 5 Steps to Well being

<u>5 steps to mental wellbeing - NHS</u> (www.nhs.uk)

What to do with an EHCP (Education & Health Care Plan)?

- A parent shared her worries about her child returning to mainstream school with an EHCP but not knowing what was happening. It is difficult to know if the return to mainstream school is the best decision for their child when you don't know what is happening.
- Although a named person has now been identified, the school have said there is no 1:1 support available in school, their Psychiatrist has left and the TAF has been closed.
- It was felt that schools need to have a lot more knowledge and understanding of how to support young people with Autism. Even though schools should have a register that highlights who has Autism, teachers are often not aware.
- 06re support 5s needed for parents who are struggling with managing these situations.

Top Tips

- Managing the unknown is very difficult for parents
- Being able to advocate for your child is so important. Parents need to keep raising the issues. This can be very frustrating.
- Looking after yourself as a parent and boosting your energy levels is really important. Our parent volunteer shared that they find eating a boiled egg really helps to boost her energy levels and will have a 'Protein Egg' on hand. Finding something you can do or eat to boost your energy levels can be helpful.

PDA (Pathological Demand Avoidance)

- A parent shared her worries about how to support their son who has PDA. At home it is easier to reduce demands but it is really difficult to reduce demands around things that need to be done as part of everyday life e.g. going to school.
- There are so many issues it is overwhelming and difficult to know what to focus on.
- Demand avoidance is a real issue. When ever you ask him to do something he will do the opposite even if this is unsafe e.g. running out into the middle of the road when told not to.
- He doesn't like to stand out and will mask at school.

Top tips form Clinicians

- Have a look at Newsletter there are some top tips from a parent Volunteer whose son has PDA.
- Find small rewards rather than focusing on working towards a large reward.
- Use knowledge of your child's strengths to help them in this case a strength was them wanting other people to be safe. . Use this to help him spot danger and work out what mum would need to do to keep safe
- Encourage your child to be helpful. This can increase confidence and helps them to see they can be part of solving problems rather than being a problem.
- Find activities that can help them wind down after a day at school.
- Be visual. If a particular journey is causing difficulty work through it on a map.
- Find ways to meet their sensory needs. Your child may need to run to work of some energy.

PDA Society – Pathological Demand Avoidance – Part of the Autism Spectrum

PDA (Pathological Demand Avoidance) is widely understood to be a profile on the Autism spectrum, involving the avoidance of everyday demands and the ue of 'social strategies as part of this avoidance. PDA individuals share autistic characteristics and also have many of the 'key feature's' of a PDA profile

A parent recommendation –

Amazon.co.uk : the new teen age book

The New Teen Age
Dr Ginni Mansberg & Jo Lamble

Ginni and Jo address both the physical and psychological issues faced by teens in this new age of social media and 24-hour devices, equipping parents and carers with sound strategies for navigating everything from parent-child tensions and peer pressure online and in the schoolyard to questions around food, sleep, exercise, screentime, body image, hormones, sexual development, skin, academic pressure and so much more. Packed with empathy and no-nonsense advice, *The New Teen Age* is a comprehensive guide to raising happy, healthy humans in our rapidly changing world

- Avoid direct demands.
- Try to make situations fun and enjoyable.

Managing Non Epileptic Seizures

- A parent shared their worries about their daughter who will be transitioning to Adult mental Health Services and is having non epileptic seizures. This can be a way of shutting down.
- Preparing for the transition to adult services has been difficult.
 Advice has not been consistent. Although their daughter is approaching 18 she finds it difficult to manage telephone calls and retain information. She received a triage call from Adult Mental Health Services but didn't know who had called her.
- The parents have only just found out that In order to have an EHCP, a request for an assessment needs to be made before her 18th birthday.

Top tips for helping your child through non epileptic seizures.

- Make sure they are safe in their environment
- Offer reassurance. Ask if they are Ok. Are they able to communicate?
- Help them to Ground themselves by talking to them describe what
 is in the room, ask them if they can feel the floor, bring them back
 into the moment,
- Keep calm
- Following the event, spend some time trying to soothe her with things that are familiar. This can make her feel safe.
- Holding Ice against them can help to ground them.
- Make a note of what is happening
- Try to keep a diary of seizures this can help to identify patterns and will be really useful information to share with Adult Services.
- When they are relaxed and calm try to have conversation about what helps them to relax, create a sooth box / bag.

Self Harm

- A parent shared that her daughter self harms. When ever she is in a dark place, whatever you suggest trying doesn't work. Self-soothing has become self-harming.
- A parent shared that their 15 yr old daughter self-harms and naturally finds this very difficult. They have found some items in their daughter room that they could be used to self-harm. Do you confront them about these items? How do you remove them but maintain trust with your child?
- Parents shared that they have removed items form their child's room without telling them. This hasn't caused a problem.

Top Tips from Clinicians

- CAMHS Would advise parents to remove any items that could be used to self harm. Where possible do this in front of the young person.
- Try to be open and honest about this. However, talking about items can bring a focus onto the self-harm and cause more distress. Parents may need to make a judgement on whether talking about the items causes too much distress.
- Self-harm brings with it a feeling of guilt making it difficult for young people to talk about it.
- Find moments when you can talk indirectly about things that

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Resources to help parents to think about their own well being.



self-care-assessmen t.pdf



self care assessment and plan

- may be worrying them.
- Not knowing what your child is doing can be difficult but do not ask direct questions about the self-harm
- Find a signal that your child can use to indicate that they are struggling but make an agreement that they don't have to talk about it.
- Many young people do not want to talk about self-harm because it makes them have to face up to things.
- Parents make wonder why their child will talk to others but not them.. Very often young people do not want to say things that they think will hurt and upset their families.
- Guided breathing can be helpful. Look at 'Calm Breathing' App and the U-Tube video 'Headspace' which provides guidance for 3 minutes of mindfulness / wellbeing.
- A parent asked for advice on how to support their daughter who says that she wants to be harmed by someone else. Self-harm doesn't match the pain inside. Clinician advised that it is important to have a safety plan in plan and to call the police if they are concerned about he immediate safety. It is important to seek help from CAMHS and to have a discussion with clinicians about an individual plan of care.

Parent Well Being

- It is really important for parents to look after their own well being
- Doing things to look after yourself as a parent is a good way of modelling to young people how to manage situations.