

Getting it Right for Every Child with PANS or PANDAS

Case Study: 'Ross'



This illustrative case study combines symptoms and experience of multiple children with PANS or PANDAS into a fictional child called Ross.

The study then looks at how the team supporting Ross can look at his symptoms through the lens of the Scottish 'Getting It Right For Every Child' (GIRFEC) model, and think about how to support him.

Ross is 11, and lives with his family in rural Scotland. Ross enjoys watching and playing rugby, and going to scouts.




He has just started S1 at the local Academy, is enjoying school and has a good group of friends that he has had since primary school.




In the November after starting Academy, Ross started to get anxious and angry, he didn't want anyone touching him or his stuff.

He would be really unkind to his sister and parents, making rude comments about them that he said were 'just banter' and started swearing profusely.




Attempts to talk to Ross about his behaviour seemed to make the situation worse, not better.



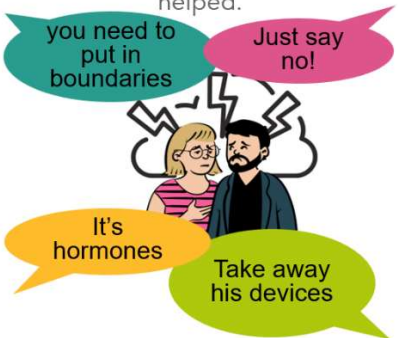
He stopped attending school and going to rugby and scouts. He wasn't even interested in watching the 6 Nations on the TV.

Ross would be awake late into the night, telling his parents that he couldn't sleep. He stopped wearing his trademark rugby tops, and would only wear hoodies and joggers or pyjama bottoms.



He was reluctant to go out of the house, and if he did, he would only do so after triple checking all the doors and windows were locked.

Ross's parents were really struggling and received lots of advice from different people - but none of it helped.



you need to put in boundaries

Just say no!


It's hormones

Take away his devices

They knew something was wrong - It was like their child had woken up one morning with a new personality.




Ross's parents couldn't think of anything that might have upset Ross - quite the opposite - they'd just had a great holiday in Spain in the October holidays, although they had all come home suffering from a bug.




Ross was referred to CAMHS by the GP, but his parents have been told that it might take 6 months before he is seen.

Things at home became so challenging that Ross's Mum had to give up work, and stay home to look after Ross.



Someone suggested that Ross's parents investigate PANS and PANDAS. They thought it made sense, and passed information to the GP.



The GP said that they had never heard of PANS or PANDAS, and thought CAMHS was still the best route.

What can we do to help Ross?

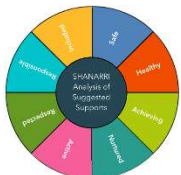
Because Ross' symptoms are complex, using the GIRFEC National Practice Model as a structure to analyse them, can aid in gaining a deeper understanding, and can support in considering actions for a child's plan.



Use the **SHANARRI** indicators to consider the impact of Ross' symptoms on his well-being. Because many of Ross' symptoms may be hidden or masked it is important that this is done as a discussion.



Use the **My World Triangle** to think about what Ross' world looks like, and how it has changed. Think about what helps Ross now, as well as the impact on his wider family. What are Ross' short and long-term goals?



Consider what supports might help mitigate the challenges identified against the **SHANARRI** indicators, using information gathered in the **My World Triangle** to consider what might work for Ross.

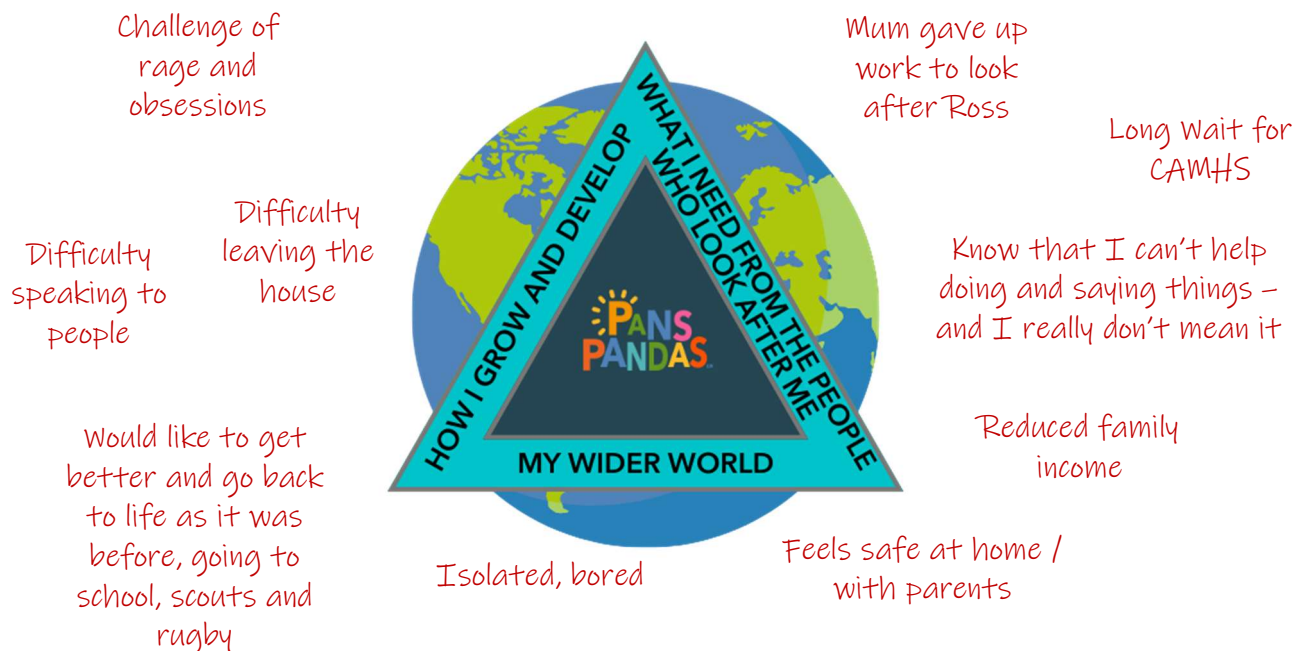


Review and prioritise the identified supports, taking a step by step approach so as not to overwhelm Ross. **Ross' voice in this process is vital.** Identify which supports to try first, what they will look like, and when they will be reviewed. These should be documented as part of **The Child's Plan**.

It makes more sense to document both parts of the SHANARRI analysis together, so we will look at the My World Triangle first.






My World Triangle




Using the My World Triangle, we can gain a picture of what the world looks like for Ross, and use it to guide in considering possible supports.



SHANARRI Analysis

Using the SHANARRI wellbeing wheel we can look at how Ross' symptoms and possible illness are impacting him, and consider what might help.

Indicator	Challenges	Support
Safe 	<ul style="list-style-type: none"> Ross's obsessions may make him feel unsafe. There is a risk that his rage may lead to someone in the family getting hurt or self-injurious behaviour. With Ross's Mum giving up work, the family may need financial support The long wait to see CAMHS and lack of knowledge by GP may lead the family to feel insecure. 	<ul style="list-style-type: none"> Understanding of symptoms by everyone working with Ross Analysis of any potential risk – are there patterns in behaviour / triggers? Plans in place for coping with common scenarios Planning for Ross' emotional safety – ensuring a safe, predictable environment Consider support through local carers service – investigate Carers Support Payment
Healthy 	<ul style="list-style-type: none"> The priority for Ross's health is to see a knowledgeable clinician, who will be able to give Ross a full medical assessment, and rule in or out PANS / PANDAS or any other condition. In the mean-time Ross should be supported with the management of his symptoms 	<ul style="list-style-type: none"> Are there any possibilities to speed up assessment? Are there any other professionals who could be involved in supporting the family? Investigate if Ross qualifies for Child Disability Payment
Achieving 	<ul style="list-style-type: none"> Currently not attending school. Will not be gaining sense of achievement through Rugby / Scouts either, as stopped attending. Important to understand Ross' baseline of skills and if they have been impacted. 	<ul style="list-style-type: none"> Key staff at school to take PANS PANDAS UK Education Training. Take small steps – with a focus on what Ross will be able to do, and what he might enjoy. Consider options for how work could be done - Outreach service / working online / neutral ground
Nurtured 	<ul style="list-style-type: none"> Ross's obsessive thoughts around people touching his things, anxiety and rage will likely lead to a challenging environment at home As Ross is no longer going to school or his usual activities it is possible his friendships may struggle Ross's Mum may start to struggle with looking after Ross 24/7 	<ul style="list-style-type: none"> Peer support available through PANS PANDAS UK support group Awareness and understanding by all involved in supporting Ross Consider if possible to access family support through social work? Respite care / carers support services
Active 	<ul style="list-style-type: none"> It is likely that the main barrier to participating in activities are his symptoms, but there may also be issues around embarrassment. Are there activities Ross likes doing on his own / with family? 	<ul style="list-style-type: none"> Consider different activities that Ross might manage Investigate possibility of 1:1 sessions (Is there any funding that could support this?)

Respected 	<ul style="list-style-type: none"> It is possible that the long waiting list for support, and the unhelpful suggestions given to his parents will lead to Ross not feeling respected. This is an area where more conversation would need to take place with Ross to understand if he felt like his voice was being heard. 	<ul style="list-style-type: none"> Awareness and understanding by all involved in supporting Ross Ensuring Ross's voice is heard Trauma-responsive approach Carers support services Mentors / Role-models Plan in place for when symptoms escalate.
Responsible 	<ul style="list-style-type: none"> It may not be realistic to expect Ross to manage behaviours that are caused by his illness. Holding him fully responsible during these times can increase his distress and make the behaviours worse. 	<ul style="list-style-type: none"> Understanding of PANS PANDAS by all people in contact with Ross Implementing flexible boundaries Using positive reinforcement and a nurturing approach Offering appropriate flexible opportunities for building responsibility
Included 	<ul style="list-style-type: none"> Ross's issues with leaving the house, going to school or activities will impact his feelings of inclusion. Ross's illness will also have an impact on social opportunities for the whole family 	<ul style="list-style-type: none"> Understanding of PANS PANDAS by all people in contact with Ross Determining if there are any activities Ross might try - individual / online / small groups. Peer support available through PANS PANDAS UK support group Family respite Supporting the family in seeking financial support if appropriate.

Child's Plan

The following were identified as the first steps in supporting Ross and his family, with a focus on ensuring safety and support for Ross and his family, increasing others understanding of Ross' symptoms, and investigating options to ensure Ross' right to an education can be met while he is unwell.

1.	Lead Professional (DHT), Pastoral Care teacher and PT ASN to take PANS PANDAS UK education training.	S H A N A R R I
2.	School to investigate e-sgoil, and if there are any spaces.	S H A N A R R I
3.	Lead Professional to contact Social work to see if it might be possible to get support from a family support worker.	S H A N A R R I
4.	Ross's Mum to register with local carers support service, and speak to primary school about registering Ross' sister as a young carer.	S H A N A R R I
5.	Ross' parents to discuss and agree plans with Ross and his sister for when things are challenging, to ensure everyone is kept safe.	S H A N A R R I
6.	School nurse to meet with Ross and his mum to see if there is anything they can do to help make things easier at home.	S H A N A R R I



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