

Support with behaviours of concern

You are not on your own....

..... we often talk to parents who feel that their son or daughter is the only one who displays behavioural challenges – they feel they personally are ‘failing’ and ‘should be able to avoid them’. However, rest assured your child is not the only one that displays these behaviours, and you are actually probably coping much better than you think.

In the moment itself, or the days that follow, sometimes it helps to seek support and/or a listening ear from outside the family unit and here are just a few places you could look at depending on your needs.

If you want to talk to us about behaviour difficulties, please call our helpline:

01332 365676

Monday – Thursday 9am – 5pm

Friday 9am – 1pm

We are here to help.

PWSA UK Support Line - Our support line is available via phone Mon-Thurs 9-5 and Fri 9-1, or you can email supportteam@pwsa.co.uk and one of the team will get back to you – sometimes it’s advice and guidance, sometimes it’s just a listening ear that’s needed.

Online Peer Support - PWSA UK has its own closed Facebook group for parents to share their experiences and ask other parents for help and ideas – this is a great support network and great friendships form as a result – as everyone here ‘just gets it’ (PWSA UK Community Hub).

PWSA UK Website (www.pwsa.co.uk) – Here you can find our leaflets with information, help and ideas regarding behaviour in both children and adults.

Other PWS organisations around the world (www.ipwso.org/understanding-behaviours) – IPWSO’s (International Prader-Willi Syndrome Organisation) has useful information from a global perspective and in addition to PWSA UK other countries are fortunate enough to have their own association too, and useful information can be found on their websites. You can also find IPWSO Famcare leaflets on subjects like skin picking, managing meltdowns, coping with change etc.

Bild (www.bild.org.uk/positive-behaviour-support-pbs) – An organisation that work to ‘help those supporting people with complex needs’. They have lots of useful information about the use of Positive Behavioural Support and support can be obtained from their team of experienced PBS consultants – they say the overall aim of PBS is to improve the quality of a person’s life and that of the people around them’.

The Challenging Behaviour Foundation (www.challengingbehaviour.org.uk) – An organisation that is ‘the charity for people with severe learning disabilities whose behaviour challenges’. They offer support for families and professionals of both children and adult, via a helpline and online resources too.

Family Lives (<https://www.familylives.org.uk/>) is a national support charity providing help and support to families who are struggling with challenging behaviour and lots more.

CAMHS are the NHS services that assess and treat young people with emotional, behavioural or mental health difficulties. CAMHS support covers depression, problems with food, self-harm, abuse, violence or anger, bipolar, schizophrenia and anxiety, to name a few. To find your nearest service, follow this link - <https://www.nhs.uk/service-search/other-services/Childrens-Adolescent-Services/LocationSearch/691>