

## Q&A (Winter – Spring 2023)

### Issues in Teens & Young Adults

Questions have been **edited** for length and privacy.

**Q:** Our son has 22q. He's 18 and exhibiting signs of OCD behavior. Anything related to OCD would be helpful, as well as suggestions for when an individual doesn't recognize or accept that they have a mental health issue.

**A:** Please see our sheet on "Anxiety Disorders". If the thoughts and behaviors your son is having affect his daily functions, please seek medical help to obtain a diagnosis. Possible treatments include cognitive behavioral therapy and medications.

Individuals with 22q11.2DS may indeed not recognize or accept that they have a mental health issue. Please check with your healthcare provider regarding possible psychoeducation, which may help your son understand his diagnosis, symptoms, and potential treatment.

**Q:** My son is 17 yrs old. He was diagnosed at 11 with 22qDS. My biggest struggle is helping him to transition to being a responsible adult. He lacks motivation and direction and no matter how I try to encourage and help him to pick a study or career path he struggles to stay focused, lacks organisational skills and just keeps saying he doesn't care when I tell him he needs to try to progress into the work environment. He over relies on me and I do indulge that by doing too much for him but when I try to get him to be more independent he has melt downs and gets very frustrated. Is this him just being a teen or is this associative with 22 QDS?

**A:** Please consider a full check up to identify and manage any medical and/or mental health conditions that may be present (see Table 1 of the [Updated clinical practice recommendations for managing children with 22q11.2 deletion syndrome](#)).

Emotional or temper outbursts may be a sign of untreated or undertreated mental health problems and/or a mismatch between expectations and abilities. Updated cognitive testing may be helpful.

**Q:** My daughter is 24 with 22q. (1) How do we find a good psychologist for her now? (2) How do we get her to set realistic goals? She has no urge to live on her own or be more independent. When we talk to her about her future her ideas are grandiose and not very realistic. (3) How do you tell if someone with 22q is safe to drive? She was able to get her license but has a hard time with directions. Visual/spatial is not great. She continues to have close calls. How can we know if she is safe?

**A:** (1) Please see "Finding a Care Provider" on Page 2 of "What Parents Can Do for Their Children". The care provider needs to be knowledgeable about 22q11.2DS and treat the mental health issues in the context of all the co-occurring conditions. (2) Please see "Setting Realistic Goals" on Page 2 of "What Parents Can Do for Their Children" with respect to cognitive testing and redirecting and setting up a structured routine. (3) Some individuals with 22q11.2DS are indeed in the same situation. Please consult the primary care provider and optometrist about driving safety issues and possible evaluation.

**Q:** My 11 year old son with 22q is lately becoming more difficult and seems more unhappy within himself, he is more lazy, wants more days off, more gifts, more sweets, pushes off bed time, refuses to help out at home even taking a towel for bath time is a huge effort for him. I find it harder to reason with him than in the past. In school he is doing well academically, physically he's weaker. (1) Any thoughts how this might be related to 22q development? (2) Whom would you recommend to help me understand him better.

**A:** (1) Youth with 22q11.2DS tend to be less mature than their peers. However, please consider a full check up to identify and manage any medical conditions that may underlie these changes (see Table 1 of the [Updated clinical practice recommendations for managing children with 22q11.2 deletion syndrome](#)). (2) Record and discuss the changes with his healthcare provider to look out for any treatable mental health issues.

## Q&A (Winter – Spring 2023) – continued

### Issues Related to Schizophrenia

Questions have been **edited** for length and privacy.

**Q:** We heard that individuals affected by 22q were disproportionately affected by disorders such as bipolar disorder/schizophrenia. Is there any research to validate these claims? If so, are there specific recommendations as to “red flags” to be on the lookout for in our children/teens?

**A:** There is no evidence that the risk of bipolar disorder in individuals with 22q11.2DS is greater than that in the general population. However, individuals with 22q11.2DS have a 20-fold higher risk of schizophrenia. About 1 in every 4 to 5 adults with 22q11.2DS will develop schizophrenia. Please consult the [Updated clinical practice recommendations for managing adults with 22q11.2 deletion syndrome](#) for more information and for the relevant research studies referenced that cite the substantial evidence about this..

In terms of “red flags”, please keep an eye out for changes in emotions, thinking, sleep, fatigue, behavior, and overall functioning. Worsening of emotional or temper outbursts may be a sign of untreated or undertreated mental health problems, including schizophrenia, and anxiety disorders that are more common than schizophrenia in 22q11.2DS.

**Q:** Since those with 22q are more likely than the general population to have mental health issues, what are the common signs/symptoms we should be alert for in case we need to seek treatment? Specifically what to watch for to identify anxiety, OCD, and schizophrenia.

**A:** Please see above regarding “red flags” to look out for. Table 2 **Signs and symptoms representing a change from baseline that may suggest a treatable psychiatric illness** from the [Practical guidelines for managing adults with 22q11.2 deletion syndrome](#) (2015 version) is an excellent resource.

**Q:** Solian (Amisulpride) is used in Europe to treat psychosis and schizophrenia. Is Solian available in the US to be used off label for treating mental illness? If not, do you foresee this changing in the near future? Is the International 22q11.2 Foundation working to make this drug available?

**A:** Our Foundation cannot comment about individual medications across jurisdictions. Please check information from the US Food and Drug Administration (FDA) for conditions for which the medication has been approved, and the [Updated clinical practice recommendations for managing adults with 22q11.2 deletion syndrome](#) with respect to recommendations for the treatment of schizophrenia and other psychotic illnesses in 22q11.2DS.

**Q:** (1) I know that schizophrenia is one thing that is connected with 22q11.2 but I was wondering if there is any more specific research to what specific genes that is more common for. (2) I am also interested in learning other mental health issues associated with the different genes within the chromosome specially anxiety & ADHD and if there is any research on helping to address any of these, particularly those that don't involve medications.

**A:** (1) Researchers are still working hard to understand the genetics of schizophrenia. For the latest research, please have a look at these articles: [Genetic contributors to risk of schizophrenia in the presence of a 22q11.2 deletion](#) and [Genome-wide tandem repeat expansions contribute to schizophrenia risk](#).

(2) Information about genes in the chromosome 22q11.2 deletion region is included in these reviews: [Molecular genetics of 22q11.2 deletion syndrome](#) and [22q11.2 deletion syndrome](#). Page 2 of each of our “Anxiety Disorders” and “Attention Deficit Hyperactive Disorder (ADHD)” information sheets mentions non-medication strategies for management. The mainstay of treatment for schizophrenia is antipsychotic medication (see Page 2 of the “Psychotic Disorders” sheet). And of course, contact your doctor or healthcare provider with any concerns.