

## What Parents Can Do for Their Children

Mental health is often an area of significant concern for parents of children and adults with 22q11.2 deletion and duplication syndromes. **Psychiatric conditions are treatable illnesses, and individuals can recover.** Parents can play an active role in decreasing the impact of their children's mental health conditions.

### Help Reduce the Risks

- 1. Help the children maintain a healthy lifestyle**
  - Eat a balanced diet
  - Do lots of physical activities
  - Establish good sleep habits
- 2. Help/remind the young person to avoid alcohol and drugs**
  - The use of marijuana increases the risk of developing mood disorders and a psychotic disorder (e.g. schizophrenia).
- 3. Find sources of excess stress and actively reduce them**
  - When a person's capacity does not match what the environment requires, this can lead to stress. For example, if the child can handle a social situation for just one hour but not more, consider arriving late or leaving early from a visit.
  - Be vigilant about the presence of external stressors such as bullying.

### Regular Assessments

Children with chromosome 22q11.2 differences tend to have multiple medical issues. For the sake of early detection and treatment, it is important **not to overlook mental health.**

Input from parents / caregivers is often crucial to help healthcare providers make a diagnosis – for example, to be able to determine if the symptoms are part of a physical health condition such as a thyroid problem or are a part of a treatable mental health condition.

### Detect and Manage Problems Early

- 1. Identify problems early**
  - Treating problems early helps achieve the best possible outcome.
  - Parents and caregivers are in the best position to recognize when changes occur and can help bring them to the attention of the healthcare provider.
- 2. Record changes and inform healthcare providers**
  - Worsening of emotional or temper outbursts may be a sign of untreated anxiety or psychotic illnesses.
  - Changes in emotions, thinking, behavior, and functioning may be early signs of mental health issues.
  - See Table 2 from **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 \(2015 version\)](#)

## What Parents Can Do for Their Children (continued)

### Set Realistic Goals

Some individuals may have goals that are unrealistic and far beyond their capabilities. They may not understand or accept that they have mental health or cognitive issues. Some may be unwilling to admit that they need help.

Possible strategies found helpful include:

- **Discuss** dreams vs. realistic (achievable) goals
- **Redirect** the young person to other areas of interest
- Establish a **routine** that provides structured, fulfilling tasks with appropriate supervision
- Review neurocognitive test results and recommendations to help understand the **developmental age**

### Talk to Your Child about Possible Mental Health Issues

#### When to talk

- Use the child's **developmental age** (not chronological age) and **emotional maturity** as a guide
- Talk about mental health as part of other natural conversations about health

#### How to talk

- Be **informed** about 22q11.2DS or 22q11.2DupS
- Be **proactive**
- Be **open**
- Draw **parallels** between mental health and other features of 22q11.2DS or 22q11.2DupS
- Use **suitable** and **positive words** that the child can understand
- Consider asking your healthcare provider for advice

### Finding a Care Provider

The counsellor, psychologist, family doctor, or psychiatrist should be informed about 22q11.2DS or 22q11.2DupS. Mental health issues in the affected individual need to be assessed and treated in the context of:

- Language abilities
- Thinking and learning abilities
- Overall functioning
- Physical health conditions

Family doctors and psychiatrists can prescribe medications. Psychologists perform neurocognitive / psychoeducational assessments..

As for all healthcare, consider whether your health insurance covers the type of care to be provided.

See: [Mental Health Providers – Tips on Finding One](#) from Mayo Clinic, AZ, USA

### References / Resources

- [Updated clinical practice recommendations for managing children with 22q11.2 deletion syndrome](#) – 2023
- [Updated clinical practice recommendations for managing adults with 22q11.2 deletion syndrome](#) – 2023
- [Cognitive Development And Mental Health](#) – 14 videos from 22q11 Europe - 2022
- [Parents' perspectives, experiences, and need for support when communicating with their children about the psychiatric manifestations of 22q11.2 deletion syndrome \(22q11DS\)](#) – 2021
- [Practical guidelines for managing adults with 22q11.2 deletion syndrome](#) – 2015
- [Mental Health Providers – Tips on Finding One](#) – Mayo Clinic, AZ, USA