

MENTAL HEALTH MISCONCEPTIONS

and Down Syndrome

PEOPLE WITH DOWN SYNDROME CAN DEVELOP MENTAL HEALTH CONDITIONS JUST AS TYPICAL PEOPLE DO. TOO OFTEN, HOWEVER, THESE CONDITIONS ARE MISTAKEN AS CHARACTERISTICS OF DOWN SYNDROME AND GO UNDER-DIAGNOSED AND UNDER-TREATED.

“IT IS IMPORTANT for parents to understand that people, including medical professionals, can attribute a patient’s symptoms to having Down syndrome, when in reality these individuals may be experiencing mental health issues and need treatment like everyone else,” explained Lina Patel, Psy.D., Director of Psychology at the Anna and John J. Sie Center for Down Syndrome at Children’s Hospital Colorado. “The clinical term for this is diagnostic overshadowing.”

TRIGGERS

Mental health issues, such as depression, anxiety, or regression (a sudden loss of clarity and social and daily living skills), frequently surface during adolescence and other times of major life transitions.

For teenagers and adults with Down syndrome, this could be during puberty, a transition from middle to high school or from high school to adulthood, or a change in routine or housing situation. It could also happen after the loss of a loved one.

“During times of transition, people with Down syndrome are asked to do more things independently,” said Elise Sannar, M.D., Psychiatrist at the Sie Center. “With the lessening of support they receive as they age, that can become harder and manifest as depression.”

WARNING SIGNS

Dr. Patel and Dr. Sannar started the first Mental Wellness Clinic of its kind specifically for people with Down syndrome. The clinic at the Sie Center emphasizes that warning signs of mental health issues in people with Down syndrome can be highly varied.

Following are some common signs that indicate someone with Down syndrome might be experiencing a mental health issue.

A loss of skills and interest in life. Withdrawal from family and friends and refraining from favorite activities are common symptoms of depression in those with Down syndrome and typical people alike.

Depression also frequently leads to people sleeping more than usual and spending time alone instead of socializing with friends.

In cases of regression, for a person with Down syndrome, family members and friends may notice an abrupt, severe decline in functioning. For example, someone who was once able to get ready for the day and take the bus to work independently may suddenly have difficulty getting dressed or even eating a meal independently.

“Signs of regression are often extreme,” Dr. Patel said. “It’s as though people have just completely checked out.”

Increased self-talk. “Adults with Down syndrome engage in self-talk as a healthy way of processing what’s going on in their environment,” said Bryn Gelaro, L.S.W., Adult Initiatives Consultant for the Global Down Syndrome Foundation. “If the frequency of self-talk increases or takes on a noticeably upset, agitated, or critical tone, it’s a big sign that something is wrong.”

Obsessive-compulsive behaviors. Repetitious routines or patterns can offer those with Down syndrome a way to exert control over situations in which they feel anxious or like they have no say. Generally these patterns are healthy as long as they are socially appropriate.

“We call these grooves,” said Dennis McGuire, Ph.D., L.C.S.W., Senior Consultant for Global. “But sometimes, under stress, people with Down syndrome can get stuck in grooves that are not productive. Parents may say, ‘Johnny used to love to go out dancing, but now, he stays home and spends his time rearranging his desk over and over.’”

FINDING TREATMENT

An important first step in helping an individual with Down syndrome overcome a mental health issue is getting a comprehensive medical evaluation to rule out physical health problems, such as hypothyroidism, sleep apnea, or hearing loss, that can contribute to changes in behavior. These physical health problems can often be treated and are not mental health issues.



A mental health professional with experience treating people with Down syndrome can then work with an individual and his or her parents, caregivers, teachers, supervisors, therapists, and others to get a comprehensive picture of his or her mental health. Based on that combined diagnosis, a provider can recommend behavioral therapy, medications, or other interventions to meet specific needs.

CHALLENGES AND OPPORTUNITIES

There can be challenges in seeking mental health care for people with Down syndrome. First, in some populations there is a stigma associated with mental health issues.

“It’s really important to remove that stigma,” Dr. Patel said. “Mental health is something we don’t talk about enough, and if we shy away from understanding that people with Down syndrome can have mental health issues, we’re negatively impacting their quality of life.”

“The bottom line is, mental health conditions are treatable,” Dr. Sannar added. “There’s no shame in getting help.”

In addition, mental health tests and screening tools used in the general population are often not sensitive enough to diagnose people with Down syndrome. That is why finding a medical professional who has treated hundreds of patients with Down syndrome and has that expertise is important.

“With our population, diagnoses are often based on an assessment of function,” Gelaro said. “Are they still being successful? Have there been changes in their activities of daily living, cognition, or memory? Those things are key.”

Medical practitioners are finding that many medications used to treat mental health conditions in the general population can be successful with people with Down syndrome. But more research is needed to assess concerns about medication sensitivities and side effects related to the treatment or its dosage. ●

EASING STRESS IN TIMES OF TRANSITION

Certain behavioral characteristics common among people with Down syndrome can make it difficult for them to adapt to major life changes.

“People with Down syndrome often have set patterns and routines,” said Dennis McGuire, Ph.D., L.C.S.W., Senior Consultant for the Global Down Syndrome Foundation. “They also rely on concrete versus abstract forms of thought, which makes it hard for them to understand and conceptualize alternatives.”

Used to their advantage, those same qualities can help prepare people with Down syndrome for an upcoming transition and give them a greater sense of control over their circumstances — lessening the likelihood of stress-induced mental health issues.

For example, visual cues, such as calendars, schedules, and checklists, as well as visits to new schools or workplaces provide tangible evidence of what’s to come.

“If teenagers leave school without an idea of what their lives may look like, they have a hard time visualizing their futures, which can lead to depression and anxiety,” Dr. McGuire said.

“Visiting different recreation or work settings before graduation helps them see what the future may look like.”

GOOD MENTAL HEALTH STARTS EARLY

From an early age, teach children with Down syndrome how to let people know when they feel uncomfortable with a situation or unprepared for a task or activity. Expression can be as simple as a specific statement, word, gesture, or sign. Learning healthy ways to manage and express their emotions can help prevent feelings of anxiety or depression throughout their lives.

