Updated Clinical Practice Recommendations For Managing Adults with 22q11.2 Deletion Syndrome


This set of clinical practice guidelines are developed for the care of individuals 18 years and older, covering life from the transition into adulthood all the way to the elderly age range. The emphasis is on periodic assessments to uncover and manage conditions that are later-onset or previously undetected.

Early diagnosis and treatment are important, and standard treatment strategies apply for each condition. Healthcare providers from different specialties need to provide coordinated care and tailor the management to suit the individual, taking into account coexisting issues, intellectual disabilities, learning disabilities, mental health problems, and the changing nature of 22q11.2DS over time. In many cases, family members and caregivers continue to be an essential part of the care team.