

Living with Costello Syndrome: Quality of Life Issues in Older Individuals

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Clinical and molecular analyses of Costello syndrome are proceeding at a rapid pace. This movement includes the delineation of the adult phenotype of this rare syndrome. In order to describe the quality of life of older individuals with Costello syndrome, a two part survey was designed to elicit objective information from caregivers regarding daily living skills and activities and subjective information from the individuals with Costello syndrome assessing self-esteem, life satisfaction and interpersonal relations. The data was analyzed in order to describe day-to-day life and continue the description of the adult phenotype, as well as determine potential impediments on quality of life for older individuals with Costello syndrome. Four impediments to quality of life for individuals with Costello syndrome were identified: desire for close relationships, lack of independence and autonomy, concerns regarding plans for the future, and the presence of major medical issues. As such, recommendations to maximize quality of life for older individuals with Costello syndrome are made.