

HEALTH CARE FOR ADOLESCENTS AND YOUNG ADULTS LIVING WITH DOWN SYNDROME

Persons with Down Syndrome (DS) are living longer. The factors responsible for this include recognition, treatment and prevention of specific health conditions; increasing availability and access to health care and research. Dynamic universally accepted health care guidelines have been useful in improving medical care.

Early detection of anomalies and medical conditions present at birth and monitoring for and treating them have improved health outcomes and quality of life for persons living with DS. The life expectancy for persons living with DS has increased 4-fold since 1970, and is now approaching 60 years. In 2010 de Graff et al estimated that there were 206,000 persons living with Down syndrome in the United States of America (of which 3,500 were 45 year old).

Some common conditions seen in persons living with DS include - heart, gastrointestinal, vision, hearing impairment and thyroid disorder. Early detection and intervention for these sometimes life threatening conditions is now the norm. Continued monitoring is still required into adulthood.

Blood disorders seen in this age group include non-worrisome low level of white blood cells and increase in volume and numbers of red blood cells. The increased risk of leukemia seen in children with DS is lowered by the age of 20 years. Compared to their counterparts without DS, adolescents and young adults living with DS have a lower risk of solid tumours such as cervical, breast, lung and colon cancers. There is however a higher risk of ovarian and testicular tumours.

The risk of cardiovascular problems like coronary artery disease, atherosclerosis, systemic hypertension and myocardial infarction is lower. A significant number in this age group will, however, have repaired congenital heart defects and evolving valvar heart problems. Cardiology monitoring is therefore recommended into adulthood. Of note there is also blunting of the sympathetic response resulting in baseline slow heart rates and lower blood pressures. This will limit the effectiveness of aerobic exercise and in general may cause blood pressure changes that can lead to fainting.

The majority of other health problems facing adolescents and young adults living DS are intertwined issues related to cognitive & mental health, sleep & exercise and weight & metabolism. The prevalence of obesity in adolescents and adults living with DS is at least 40%. Some risk factors for obesity include lower metabolism, eating disorders and low thyroid hormone levels. In addition the high prevalence of upper airway issues seen in DS often cause sleep apnoea which affects cortisol and growth hormones levels. Sleep apnoea may also cause appetite dysregulation. Complications of chronic obesity include poor mental health, metabolic impairment, hormonal imbalance and worsening of sleep apnoea.

Obstructive sleep apnoea has been associated with intensification of pre-existing anxiety and disruptive behaviors, cognitive decline, pseudo-dementia like regression and depression. As the child with DS gets older, it is therefore of paramount importance that sustained vigilance be paid to sleep pattern, mental health and weight gain. Often this may help to elucidate the cause of these significant, complex, co-occurring conditions, thus allowing for effective therapeutic interventions.

Summary of Dr George Capone's Talk at the Paediatric Association of Jamaica's Biennial Conference 2019 March 22

Prepared by Dr Charmaine Scott O.D

Paediatric Cardiologist

Founder and Director Jamaica Down's Syndrome Foundation

2019 May 07