

Special Populations as they Age

Home Care or Long-Term Care?

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Spina Bifida

- Occurs in about 2.7 to 3.8 per 10,000 births and more than 75% of people with SB live into adulthood.
- Transition from pediatric to PCP providers are often met with resistance from patients and their parents
- **Hydrocephalus** 62%—80%. Shunt malfunction is a key concern. Diagnosis can be sub-clinical such as drowsiness or lethargy, headache, nausea, dizziness, sleep apnea. Major underlying cause of death.
- **Tethered Cord Syndrome** 20%--55%. Back pain, motor weakness and/or sphincter dysfunction.
- **UTI**—the most common preventable secondary complication, 50% reported on annual basis.
- **Metabolic Syndrome** obesity, HTN, increased triglyceride, cholesterol, blood sugar, diabetes, ASHD.
- **Sleep Apnea** decreased strength in respiratory muscles, kyphosis, scoliosis, ?shunt malfunction
- **Skin breakdowns** foot and ankle when level is lumbar or sacral; buttocks when thoracic.
- **Pain** neuropathic, orthopedic; impacts QOL, mobility, osteomyelitis
- **Bone Health** decreased density, decreased Vit D, decreased physical activity, increase in RF

Down Syndrome

Life expectancy 62 years but display premature age-related changes:

- **Skin and Hair** graying, hair loss, wrinkling of skin, Alopecia, atopic dermatitis, xerosis
- **Early menopause** is a risk factor for heart disease, depression, osteoporosis, breast-cancer, and dementia
- **Vision Impairment** cataracts, visual acuity, strabismus, keratoconus; only 50% receive correction
- **Hearing Impairments** more common among adults with DS and earlier age onset
- **Seizure Disorder** increases especially for those individuals suffering from comorbid dementia
- **Thyroid Dysfunction** 40% have abnormal function, the need to have routine monitoring for med management
- **Diabetes Type 2**
- **Obesity**
- **Sleep Apnea** due to facial features, glossoptosis, small airway
- **Musculoskeletal** degenerative joint disease, low muscle tone, decreased strength, pes planus (congenital)
- **Mitral Valve Prolapse** common in 46%—57%; Early signs include fatigue, weight gain, and irritability

Cerebral Palsy

The brain injury that initially causes CP does not worsen with aging, the effects impact differently with aging:

- 2.6 to 2.9 per 1,000 births Gross Motor Functional Classification System (GMFCS)
- **Cardiometabolic and Pulmonary morbidity** higher rate of diabetes, asthma, HTN, stroke, emphysema
- **Cardiovascular** especially in non-ambulatory manifesting in fatigue, bowel symptoms, shortness of breath
- **Pain** neck, back, joint, hand paresthesia, overuse syndrome, spasticity
- **Neurological Challenges** cervical myelopathy due to abnormal movements (dyskinesia)
- **Dysphagia** deterioration of swallow, aspiration without cough reflex, malnutrition
- **Musculoskeletal** osteoporosis, Vit D def, limited weight bearing, medications (seizure), spontaneous fractures
 - **Sarcopenia** muscle imbalance, poor muscle quality, less contractile tissue, high risk contracture

Fragile X Syndrome

- Fragile X Syndrome is the most common inherited form of autism and ID. 1 in 3,600 in the general population
- The FMRP (protein) in neurons plays a vital role in synapto-genesis and synaptic plasticity and is diminished in FXS and manifests itself as hyperactivity, anxiety, attention problems, hand flapping, gaze avoidance, loose connective tissue, flat feet, high-arched palate, long face, and macro-orchidism. Cognitive deficits related to FMRP levels.
- Age related changes:
 - Brain global atrophy
 - Purkinje cell loss
 - Heterotopia (abnormal clumping of gray matter)
 - Deterioration of the corticospinal tract
 - Dendritic spine abnormalities including long, thin and immature spines
 - Tremor and Ataxia
 - Cognitive decline possibly developing into dementia
 - Improvement in disruptive behavior but an increase in anti-social behavior
 - Declines in IQ most remarkably in the verbal area and use of language decreasing over time

The Association on Aging with Developmental Disabilities (AADD)

“The Association on Aging with Developmental Disabilities (AADD) was initially formed in 1989 as a special interest group and became incorporated in 1994. AADD has a primary objective of bringing the aging and developmental disability fields together to create and provide best practices for people aging with developmental disabilities (autism spectrum disorder, cerebral palsy, down syndrome, learning disabilities, epilepsy, and intellectual disability—formerly known as mental retardation).....

The average life expectancy for people with a developmental disability was 22 years in 1931, compared to 62 years for the general population. Now, average life expectancy is 70 years for most people with developmental disabilities, quickly approaching that of the general population.....

As older adults, they are living with aging family members, living independently or in supported living/group home settings. Most people with developmental disabilities did not produce offspring, so they have little if any family support as they age, thus the increased need for the support provided by AADD.”