

The adult with Down Syndrome



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- Senior in Nursing school I met Larry- first person I had met with Down Syndrome
- Worked at CMH and took care of children with DS that were having cardiac surgery
- Went to Iowa and became interested in genetics and in particular DS. My thesis-a case study with an 8 yo girl with DS (now in her 40s)
- Over the years always involved with people with disabilities in one way or another- my best friend is now 50 something and has DS- known each other over 30 years

My Journey

- Finally, when I began my dissertation I was unsure of the topic but I knew my population
- In the course of the research I realized that children with DS have many resources but adults do not and they are a growing population
- In infancy a fair number have hear defects & other health problems. General practitioners, pediatricians as well as specialty clinics offering pediatric services do a great job caring for them

- But then they turn 18 or so and the pediatric people can no longer care for them and their needs change as they become adults.
- Adult providers are not as adept as the pediatric providers primarily because it has not been an issue and they had no experience.
- So I developed the clinic to care for adults with Down syndrome

Then they turn 18!

- Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. (WHO definition)
- Life expectancy is now 60-61 years but have some premature aging issues
- Some difference between the DS of years past and the DS we know today (expectations, opportunities, goals, dreams)

Life

- Highest level of health (physical and mental) possible
- Assess for any medical conditions and the cause or underlying cause of it
- Assess behavioral changes and consider if it is a communication to us
- Treat medical and psychological conditions as necessary and as a normal variant- not because they have DS
- Encourage healthy lifestyles and behaviors

General Considerations

- Most prevalent genetic cause of intellectual disability- 1: 733 live births
- When one thinks of DS most think of a child but our children are growing up and growing older
- Life expectancy has increased at a rate of 1.7 years annually since the early 1970s

Statistics

• England-	1955	<5yrs
• Australia-	1963	<10yrs
• Texas, US-	1973	30 yrs
• British Columbia-	1989	57 yrs
• California, US-	1996	>50 yrs
• Australia-	2004	60 yrs

**Life Expectancy since 1955
published studies**

• "Every feature of DS shows a high degree of variability with respect to occurrence (e.g., congenital heart defect) or degree of severity (e.g., intellectual disability). As far as we know, the same is true for its effects on aging."

Important Point

- What we do know now is that the health concerns of the adult with DS is different than the population without DS
- So we want to spend the next few minutes discussing the unique and not so unique health care needs of the adult with DS

Adult Health Concerns

- Adults with DS still need annual exams
- Mammograms are not necessary because the incidence of breast cancer is very low and it is a difficult test to accomplish.
- Paps are not necessary in most situations- we are screening for cervical cancer- risk factors are smoking, many sexual partners, early onset intercourse- most are not at risk

Health Concerns

- Hyperlipidemia- adults in general do not have heart disease (even with high numbers in cholesterol and obesity) Currently thought that the medications have side effects so that risk vs benefit is not positive
- I still measure but recommend lifestyle changes for treatment

Health Concerns

- Immunizations are the same
- Obesity can be a problem- their metabolic rate is about 50% of the other adults and can cause problems with joints and activity as well as some self care activities
- Hypothyroidism is extremely common and so thyroid function needs to be checked annually

Health Concerns

- Sleep apnea is a major issue- because of the small oral features, the hypotonia and the obesity (even without that) they are at risk. It can cause behaviors & depression-like symptoms. Difficult because Medicaid will pay for the machine but not the test so we have work arounds.
- Home sleep studies and low private pay rates

Health Concerns

- OCD for this population is a double edged sword- on one hand it makes them extremely functional ("the groove") and good employees. On the other hand it can get out of control- especially in reaction to stress- and become problematic.

Health Concerns

- Osteopenia or Osteoporosis (Low bone density)-Occurs in women more frequently after menopause
- However- the drugs to treat this do not seem to make a huge difference for adults with DS. There is some research now thinking the mechanism of this bone loss maybe different in this population
- CA++ and weight bearing exercise

Health Concerns

- Self talk is part of the makeup- not a concern unless it is a problem socially
- Celiac disease is not unusual and can present in behaviors or changes in bowel habits
- Visual memory- good and difficult- schedules are helpful so they tell them what to do- they never forget things

Health Concerns-Random thoughts

- Have a radar type sense about them that perceives what is going on in people around them- very sensitive to stress and anxiety in others and the household
- Many have repetitive activities and they are a source of coping and relaxation- may increase when they are stressed or they may stop when the stress is great

Health Concerns-Random thoughts

- About 1 in 10 adults are thought to have autism concurrently- therapies that work for autism also work in DS
- Grief process is different- they replay the tape and then it is over- memory books help

Health Concerns-Random thoughts

- Risk factors for onset of AD in adults with DS parallels the general population
- Age, Fam Hx, genetic susceptibility or protection (3rd copy of 21?), education, physical fitness, hormonal status (estrogen)

Health Concerns-Alzheimers Disease

- Does occur earlier because of the accelerated aging process (about 20 yrs)
- 30% develop in their 30s, 40% in the 40s and 50% in their 50s BUT 50% do not

Health Concerns-Alzheimers Disease

- 3%- 19% of adults with DS older than 65 have mild cognitive impairment
- That is 5-58 cases per 1,000 per year
- 11-33% progress to dementia over 2 yrs
- HOWEVER- virtually all adults with DS have extensive deposition of amyloid plaques and neurofibrillary pathology by 35-40 yo
- But not all adults develop dementia and there is a wide range of age of onset and severity

Incidence

- Diagnosis is difficult- no good cognitive test available
- Symptoms such as no longer doing some activity, forgetting where their bedroom is, dressing issues, forgetting family members' names
- A sense there is a dementia of old age- senses decrease, work of daily living becomes more difficult to think through

**Health Concerns-
Alzheimers Disease**

- Pre-existing cognitive impairments and individual differences in lifelong abilities
- No routine method of assessment
- Caregivers may not notice early changes
- Other aging concerns or life events can co-exist
- We do not understand "normal" aging enough to establish "abnormal"

**Diagnosis of Dementia is
complicated**

- "Unfortunately, nothing currently available is especially effective in slowing the progression of dementia"
- Includes Memantine (Namenda) and Aricept

Treatments

- Hypothyroidism
- Hearing impairments
- Vision issues (cataracts, keratoconus)
- Cancer of the testicles and ovaries
- Celiac disease
- Sleep apnea
- Alzheimers Disease

Common Medical Conditions

- Cervical subluxation
- Vitamin B12 deficiency
- GERD
- Constipation
- Boils
- Fungal infections
- Leukemia
- Osteoarthritis

- Hypertension
- Coronary artery disease
- Cancer

Less common medical issues

- Nutrition
- Weight (slow metabolism)
- Exercise
- Sleep hygiene (routines)
- Mental Health status

Health Monitoring

- History and physical exams (VS, BMI)
- Labs- TSH, Vit B12, CBC, CMP
- Hearing and vision testing
- C-spine xray x1- even if it was normal in childhood
- Immunizations (flu, Tdap, Hepatitis B, Pneumonia)

Annual medical visits

- It is different- it is sooner, they appear older than their ages in many cases, they develop cataracts, hearing loss, dementia of some type and their life expectancy is less

Aging and DS

- People with DS born in the 1950s and 1960's and still living are the strongest of the strong
- They did not have the advantages of today's world
- Children born with DS today have many advantages and will be and are quite different in how they are raised and their goals and expectations.
- This generation will be very different from the generation that is now aging

2 different generations

- Contraception/amenorrhea
- Marriage & reproduction
- Independent living
- Guardianship
- Employment

Final Health? Concerns

- Mental Health is so important and can change- only indicator may be behavior change
- Visual learners and thinkers- lists, calendars, pictures, charts
- Grieving is very different in this group
- Most love to dance, sing and regardless of what they are doing they are the best- just ask

Odds and Ends

- Behaviors are communication and we cannot just "accept" them as part of the syndrome
- Need opportunities to be of service
- Opportunity for us to make healthy lifestyle changes with our adults

- I worry about caregivers that say "well, its his only joy..." They love everything about life and have many joys and this attitude can create problems for them.
- Quote from a parent "Instead of praying for them to be healed maybe we should pray that we can be more like them"

"If people with DS ruled the world"
Dennis McGuire

- Affection, hugging and caring for others would make a big comeback.
- All people would be encouraged to develop and use their gifts for helping others.
- People would be refreshingly honest and genuine.
- We believe that a stuffy high society would not do well- just dance.

- People engaged in self talk would be considered thoughtful and creative.
- Order and structure would rule. "The Groove"
- The words "hurry" and "fast" would not be uttered. "Plenty of time" would take their place.
- News would consist of the weather and social schedules. No bad news because there was no violence.

- Self expression through art and music would be big.
- Richard Simmons would a national hero.
- There would be dances 3 times per week.
- Elvis, the Beatles, the Beach Boys, Grease and other musicals would play all the time. (or country music & High School Musical)
- Wrestling would be on TV all the time.

- There would be fewer movies but they would play over and over. Theaters would allow people to talk out loud to tell what happened next.
- People would not lie, hurt the feelings of another or keep secrets.
- So I ask what would be wrong with a world like that?



Recommended books

Thank you for your attention!

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Questions?
