Beyond ADL: Strategies for Transportation, Work/Life Modifications, Socializing and More

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How DM1 may affect my life beyond ADL?

A quick overview
A lot of solutions

Vision: Cataracts, retinal damage
Bone: Anomalies
Immune: Hypogammaglobulinemia
Skin: Pilomatrixomas

Respiratory System:
Breathing difficulties, sleep apnea

Endocrine:
Low thyroid

Reproductive:
Testosterone levels, testicular failure and gonadal atrophy in men. Weakened uterine muscle, pregnancy-related complications, and gynecological problems in women.

Cognitive Function:
Intellectual impairment, behavioral and psychological disorders, excessive daytime sleepiness

Gastrointestinal:
Gastrointestinal issues, abdominal pain, irritable bowel syndrome, constipation/diarrhea, poor nutrition and weight loss, chronic infections

Muscle: Weakness, wasting (atrophy), myotonia, pain
MUSCULAR IMPAIRMENT

• Loss of muscle strength
  • Distal weakness: 9 years (3-15)
  • Proximal weakness: 18 years (9-27)
  • Severe proximal weakness: 27 (17-37)

• Consequences
  • Decrease walking capacities
    • Walking aids
    • Wheelchair
  • Increase numbers of falls
  • Decrease grip strength
Fatigue

• 60-74% will report significant fatigue (Kalkman, Gagnon)
• Energy conservation techniques
• Fatigue does not mean not to exercise as preliminary data seems to indicate that exercising decreases fatigue level
APATHY

- 40% of DM1 individuals could present with apathy (Gallais & al., submitted)
- The lack of motivation inherent to apathy, clinically expressed as reduced goal-directed behavior, cognition, and emotion (Marin, 1991)
- Difficulty to get going or to start an activity
Environmental factors

- Support and attitudes from family and friends
- Technology
- Government and public services

(Gagnon et Kierkegaard)
Adaptations are coming more and more sophisticated as

People with disabilities constitute the nation's largest minority group, and the only group any of us can become a member of at any time.

- Disability Funder's Network
GETTING SOMEWHERE IS THE FIRST STEP

Community mobility

Driving
Community walking

- Decrease strength is related to decrease performance on the 6 minute walk test (endurance test)
  - 556 meters (MIRS 1-3)- 320 meters (MIRS 4-5)
- Decrease endurance is related to decrease community walking in other populations
- Need to be assessed by a physiotherapist
Community walking

How fast should I walk to cross a light?

• 1.14 meters/second
  • Crossing a 2 lane road (4 metres/lane) in 10 seconds (5 seconds per lane),
  • 3 seconds to get up and down off either curb (1.5 seconds per curb).
How Is it assess

What should I do?

- Keep fit as much as possible
- Weight reduction if appropriate
- Walking aids/wheelchair
- Four-wheel mobility scooter
  - Shopping
  - Walking with friends
  - Travelling inside large buildings
Driving and related tasks

Getting there
Driving not a simple task !!!!

- Getting in the car
- Driving
- Using the pedals
- Using the driving wheel
- Putting your wheelchair in the car trunk
Driving the car

• 58.5% are still driving (Gagnon, 2007)
• Potential contributing factors to difficulty related to driving
  • Fatigue
  • Foot drop
  • Cataract and ptosis
  • Hand strength
  • Neck posture (Philips & Mathieu)
  • Hypersomnolence not as much as usually thoughts
Getting in the car

• Why do I have more problem getting in the car as the disease progress ?
• I am still walking but I have major troubles getting in the car ?
Muscular impairment rating scale (MIRS)


Potential solutions

VIDÉO

• http://www.bruno.com/valet-signature-seating-valet-plus.html
Using the pedals and driving wheel

- Not often a big issue but if so consult your Occupational Therapist
  - Decrease demands on muscle strength
Transporting your manual wheelchair

• Putting the wheelchair in the trunk is often an issue as strength decrease and balance is uncertain.
Transporting your wheelchair. (http://www.braunability.com/wheelchair-lifts/chair-topper/)
Even solution from our friends from Texas

Biggest buyers of pick-up Trucks (business review)

http://www.businessweek.com/articles/2013-10-03/texas-key-to-pickup-truck-makers-success
Access-A-Top
Transporting your wheelchair

- Product lifts and stores your unoccupied scooter or powerchair (weighing up to 350 lb/160 kg) outside your small, mid-sized, or large car at the touch of a button
- Example: Bruno's ASL-700 Chariot® Vehicle Lift
Accessible Transportation

Often present in your community but need to consult your local services

- Bus
- Train
- Airline
So you got there

But not in yet
Getting in the building and more
Washington Hilton Hotel

Let’s do something
Shopping
Shopping

- Home delivery
- Internet
- Medication delivery
- Shopping cart
- Scooter in stores
**Apps and More**

- Help you to remember your shopping list
  - Remember the milk
- Comparing prices without having to go to every store
  - RedLaser
- Help you take notes, store pictures and more
  - Evernote
Leisure
Factors affecting leisure

• Lower extremity strength (Strength training)
• Fatigue (Energy conservation techniques)
• Support and attitude from family and friends
• Government and public services
• Education
• Probably also apathy

(Gagnon et al., 2008)
Bowling

http://www.achievableconcepts.us/usa_bowlten.htm
SPA
Adaptive skiing
OTHER IDEAS

• Swimming
• Horseback riding
• Fishing
• Tandem cycling
• Museum
A babysitter !!!!

And believe or not, kids will survive without you !!!!
Breaking barriers
America's Freedom Sailor
Travelling means also going to the bathroom !!!

- Make sure the bathroom are accessible (Ableroad) but what if not?
- Special products like GoGirl or special underwear
- e.g. Be confident
Travelling and tourism
Tourism

- Often an issue with decrease muscle strength
- Decrease walking abilities
- Wheelchair accessibility
National website to plan your trip

- Kéroul
- Specialized agencies
  - http://www.disabledtravelers.com/tour_operators.htm
Free for accompanying

• Air Canada, Air Canada Jazz and WestJet have implemented a “one person, one fare” policy, whereby the attendant travels free of charge
Once you entered the building

You need to socialize
Social isolation

- Social isolation should be considered a health risk. We need more scientific evidence about how to deal with social isolation.

  http://www.mcmasteroptimalaging.org/

- In the adult onset phenotype,
  - A tendency to avoid social interaction and to prefer solitude to company (Winblad & Meola)
Some thoughts to stay connected

• Community centres
• Daily call
• Take a short course (painting, photos, etc.)
• Internet
  • Facebook
  • Twitter
• Playing online games
  • Scrabbles, etc
Some thoughts to get connected

• Get involved in your community through volunteer work
• Go take a walk
• Travel tour
For your kids

• Summer camps
• Day camp
• Social skills training
  • http://www.ldatd.on.ca/programs/children-teens/social-skills-socialization-program/
• Several excellent books with practical tips to improve social interactions
  • Could help although no evidence in DM1
Working
Work

- Schedule
- Task modifications
- Voluntary work
- Sheltered workshop
- Vocational Services
- Leaving home tasks to other persons to keep energy level
Thank you

To all my colleagues for their precious help in giving my ideas and tricks
Product website

ACCESS A TOP:
http://www.advancedmobility.net/Express2.0/partmain.php?upc=1362412274

VALET SIGNATURE

BRUNO CHARIOT
http://www.bruno.com/vehicle-lift-chariot.html

Handle for bowling
http://www.achievableconcepts.us/usa_bowlten.htm
ACCESSIBILITY WEBSITE

• Ableroad
• http://www.ableroad.com
• AgeCap in Canada