

BEYOND ADL: STRATEGIES FOR TRANSPORTATION, WORK/LIFE MODIFICATIONS, SOCIALIZING AND MORE

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HOW DM 1 MAY AFFECT MY LIFE BEYOND ADL ?

A quick overview





MANY TO CHOOSE FROM BUT ...

Vision: Cataracts, retinal damage

Bone: Anomalies

Immune: Hypogammaglobulinemia

Skin: Pilonatrixomas

Respiratory System:

Breathing difficulties, sleep apnea

Endocrine:

low thyroid

Reproductive:

testosterone deficiency, 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

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

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

A lot of solutions



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 decrease fatigue level



APATHY

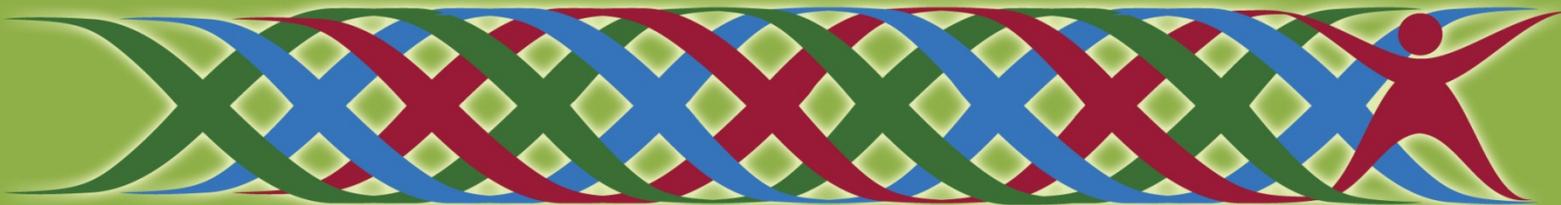
- **40 % of DM1 individuals could present with apathy** (Gallais & al., submitted)
- **The lack of motivation inherent to apathy, clinically expressed as reduced goal-directed behavior, cognition, and emotion** (Marin, 1991)
- **Difficulty to get going or to start an activity**



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**



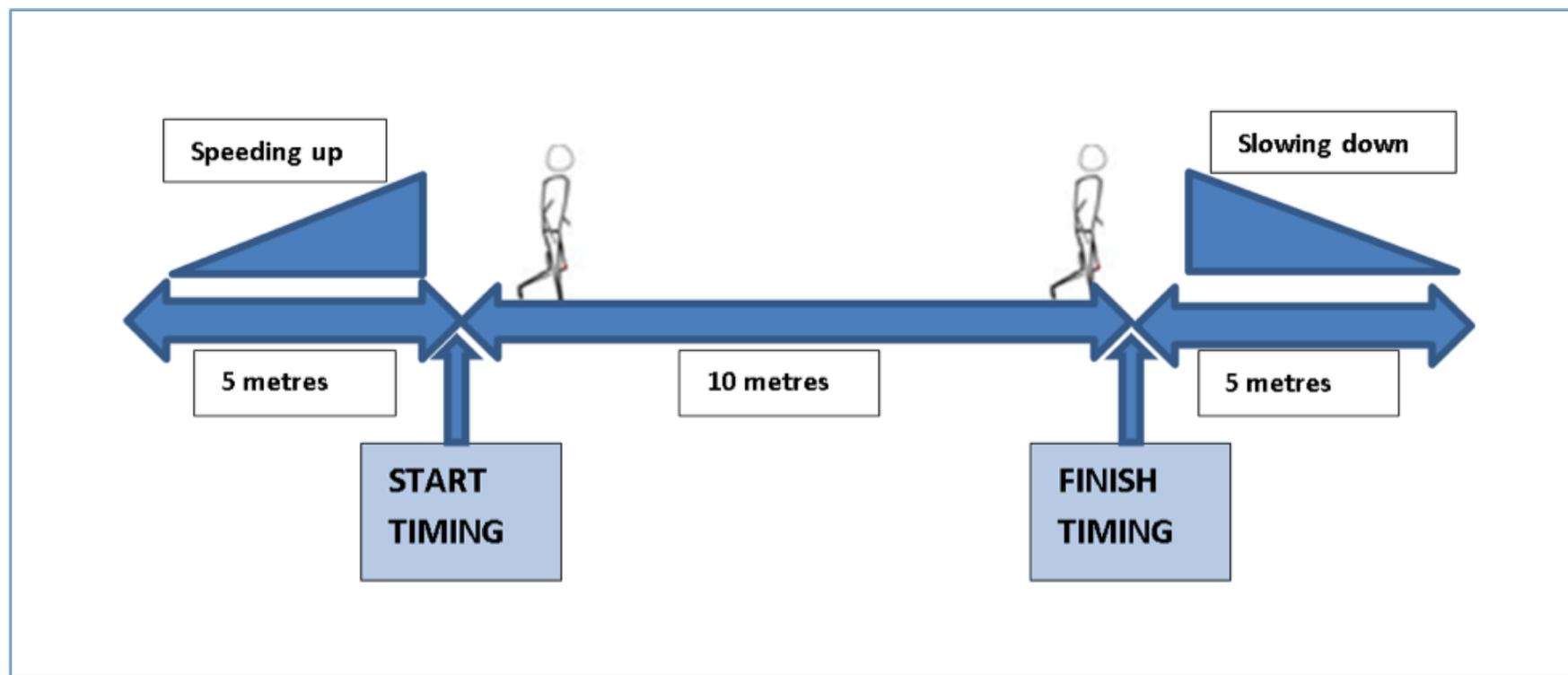
COMMUNITY WALKING

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



<http://www.mcmasteroptimalaging.org/citizens/blogs/detail/blog/2014/07/21/how-fast-should-i-walk-to-cross-the-road-safely-fast-facts-about-walking-speed>



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**

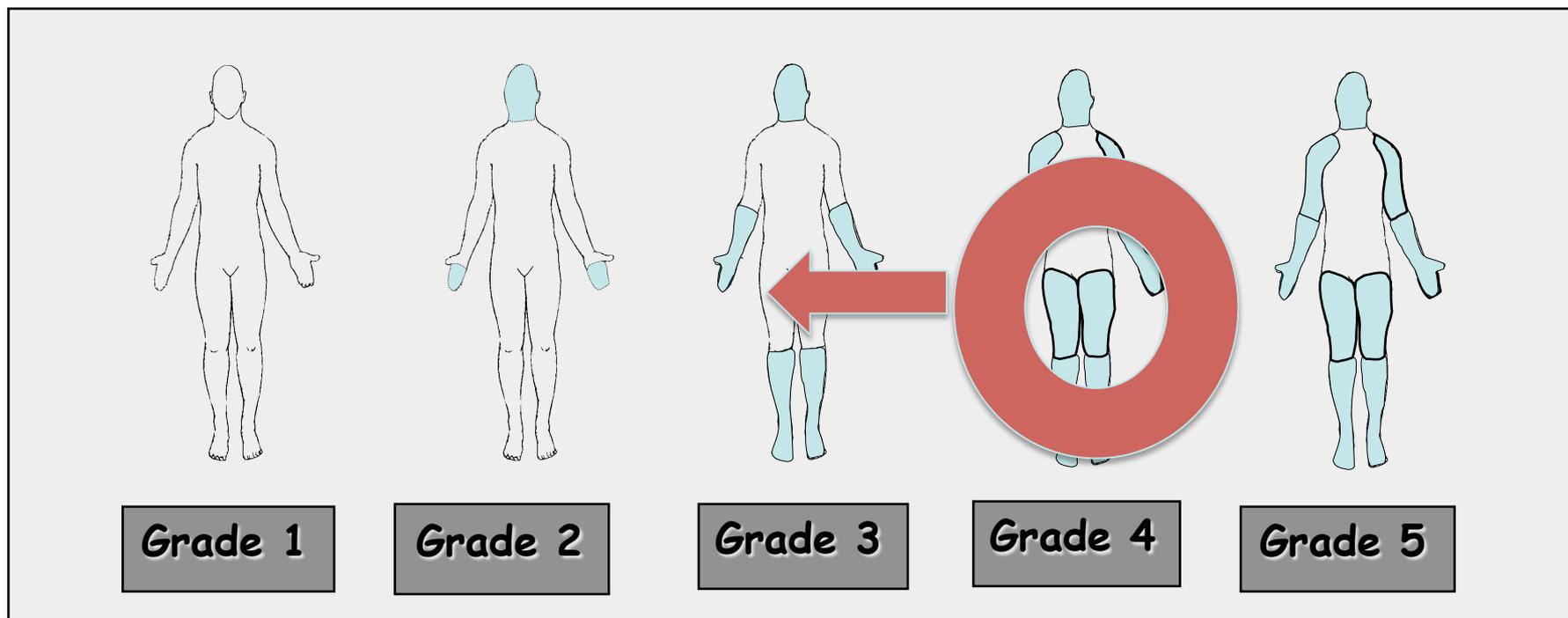


GETTING IN THE CAR

- 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)



Mathieu J et al. Assessment of a disease-specific impairment rating scale in myotonic dystrophy. *Neurology* 56(3):336-40, 2001.

Mathieu J et al. Myotonic dystrophy: clinical assessment of muscular disability in an isolated population with presumed homogeneous mutation. *Neurology* 42:203-208,1992.



GRIMN

POTENTIAL SOLUTIONS



<http://www.bruno.com/valet-signature-seating-valet-plus.html>



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.





. (<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](http://www.businessweek.com/articles/2013-10-03/texas-key-to-pickup-truck-makers-success)



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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**



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ACCESSIBLE TRANSPORTATION

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

- **Bus**
- **Train**
- **Airplane**



SO YOU GOT THERE

But not in yet





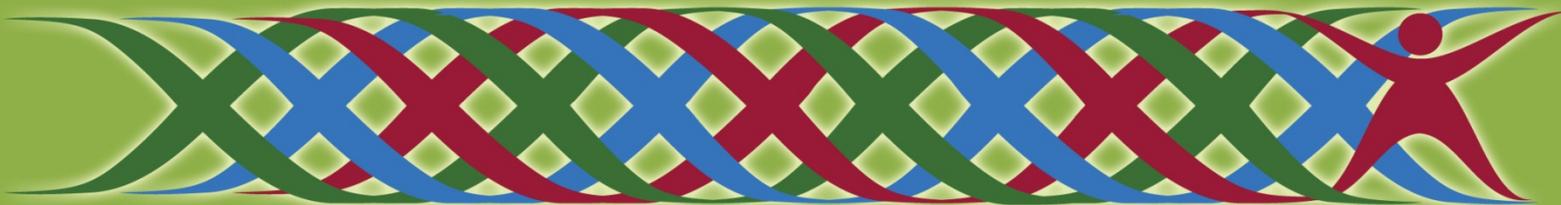
GETTING IN THE BUILDING AND MORE





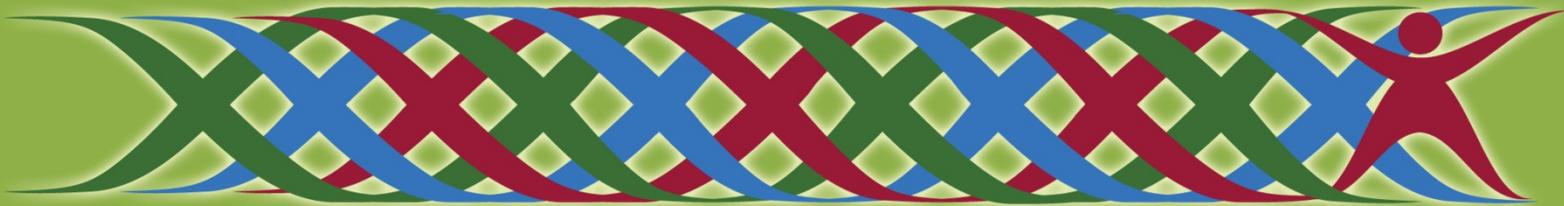
WASHINGTON HILTON HOTEL

- [http://ableroad.com/detail.php?
index=1&newID=washington-hilton-
washington-2&s=Hilton%20Hotel
%20&s1=washington&cat=8&hide=0](http://ableroad.com/detail.php?index=1&newID=washington-hilton-washington-2&s=Hilton%20Hotel%20&s1=washington&cat=8&hide=0)



LET'S DO SOMETHING





SHOPPING





SHOPPING

- Home delivery
- Internet
- Medication delivery
- Shopping cart
- Scooter in stores



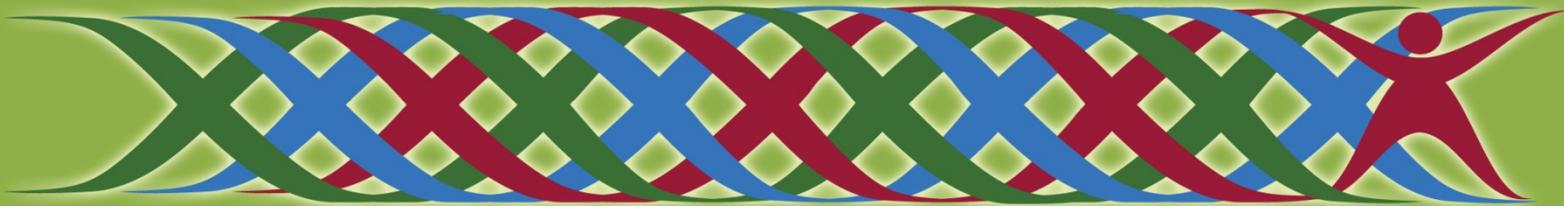


APPS AND MORE



- **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





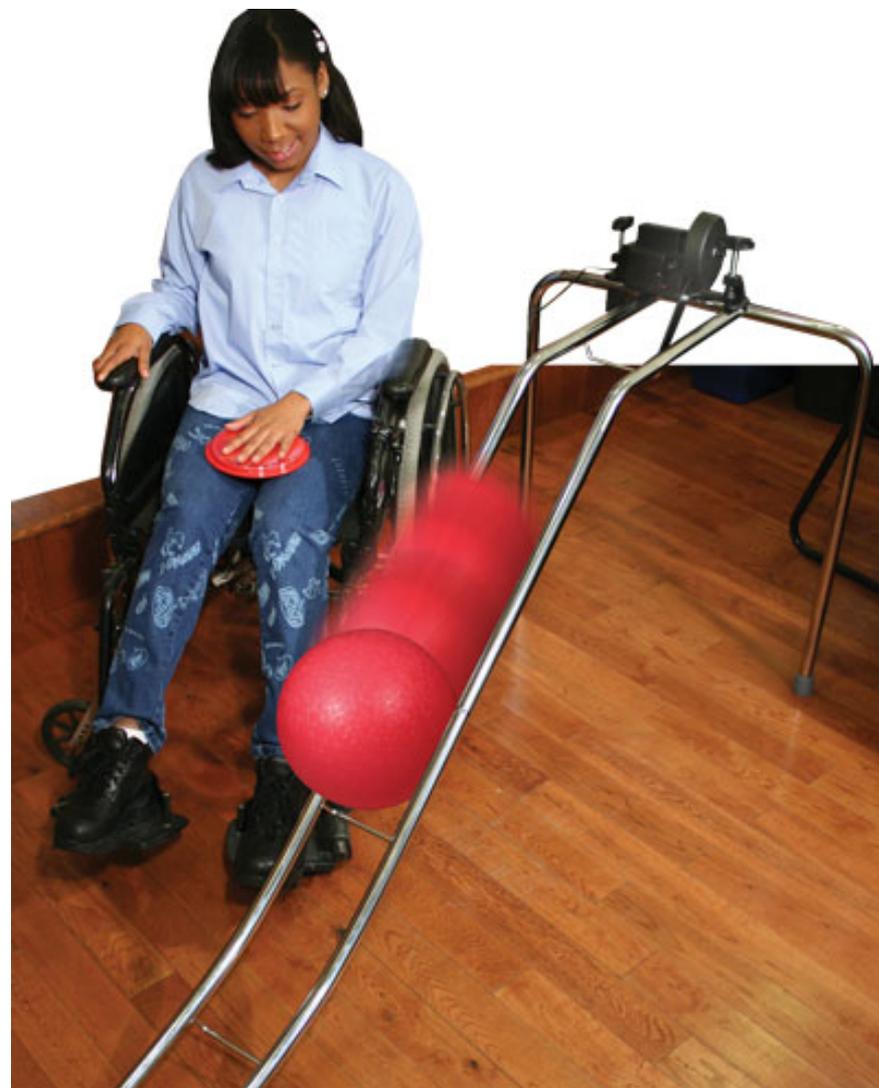
FACTORS AFFECTING LEISURE

- 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





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ADAPTIVE SKIING





OTHER IDEAS

- **Swimming**
- **Horseback riding**
- **Fishing**
- **Tandem cycling**
- **Museum**
-



FOR PARENTS ONLY

A babysitter !!!!!

**And believe or not,
kids will survive
without you !!!!!**



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BREAKING BARRIERS

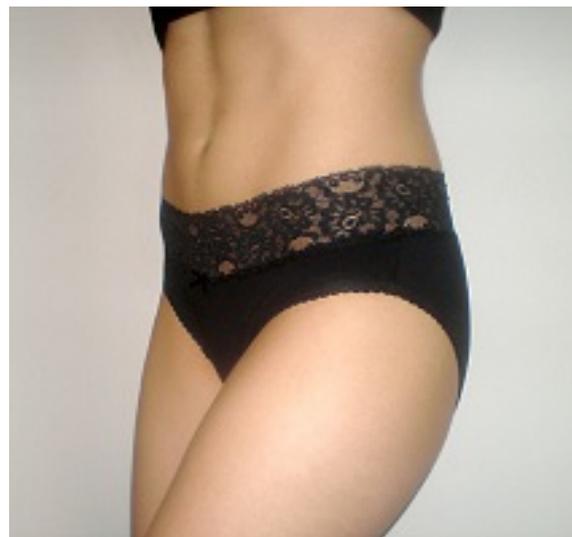
America's Freedom Sailor

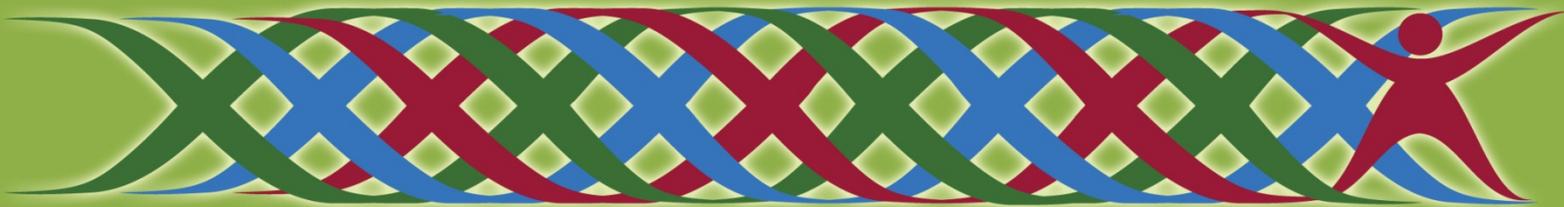




TRAVELLING MEANS ALSO GOING TO THE BATHROOM !!!

- 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

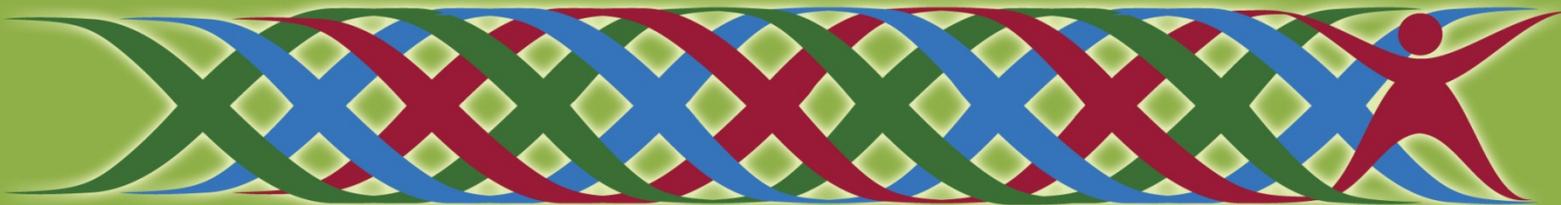
- Kéroul
- Specialized agencies
 - http://www.disabledtravelers.com/tour_operators.htm
 - <http://www.disabilitytravel.com/independent/accessible-peru.htm>





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 compaigny (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**



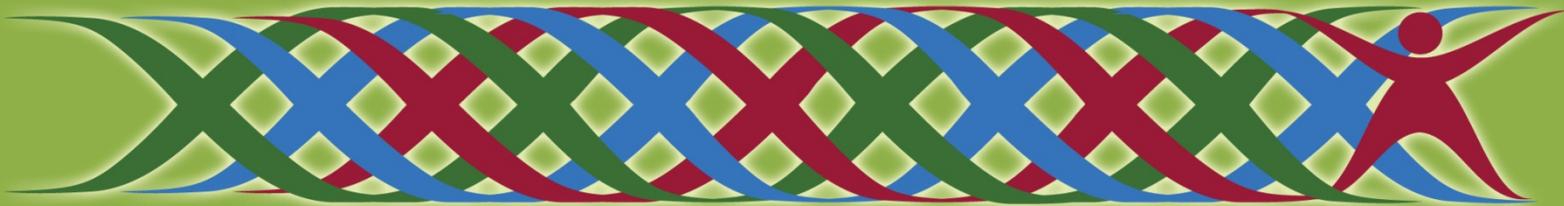
SOME THOUGHTS TO GET CONNECTED

- **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



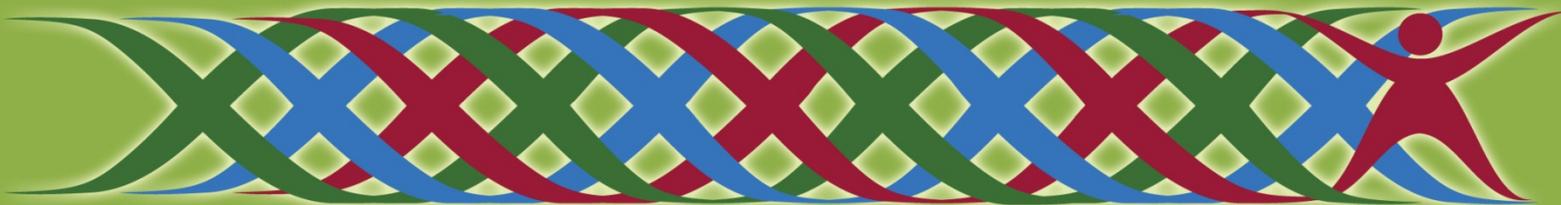
WORKING





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](http://www.advancedmobility.net/Express2.0/partmain.php?upc=1362412274)

VALET SIGNATURE

<http://www.bruno.com/valet-signature-seating-valet-plus.html>

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