

## GROWING OLDER WITH AUTISM SPECTRUM DISORDERS.


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Autism Health Wellness  
Connecting Community

## Objectives

- General overview of aging, and factors that promote successful aging.
- What is known about aging with ASD.
- Aging family caregivers, compound caregiving and future planning.
- My Health Passport and other resources



## Human Lifespan

**Jeanne Calment**  
b. 21<sup>st</sup> Feb 1875  
d. 4<sup>th</sup> August 1997  
Age: **122 years, 164 days**



**Christian Mortensen** (oldest man ever - **115 years**). "Friends, a good cigar, drinking lots of good water, no alcohol, staying positive and lots of singing will keep you alive for a long time"

Worldwide there are currently 80 verified Super-Centarians (aged 110 years plus).




## Disease and Old Age

Aging is not a disease, does not mean disease, and does not automatically include disease.

*Many abnormal changes associated with aging can be prevented or slowed enough to never appear during normal life span.*

Medical advancements → longer **life expectancy**

New research findings, health promotion/education → disease prevention → longer **healthy life expectancy**




## So What Exactly is Aging?

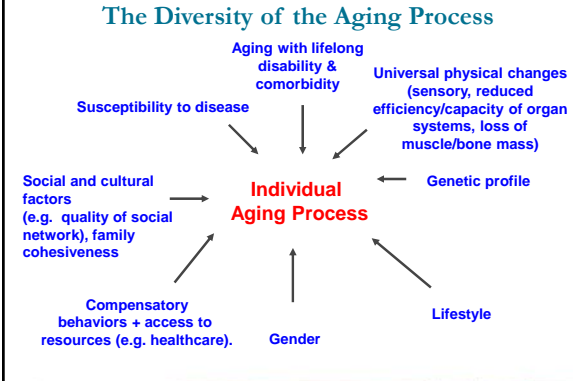
Changes that are caused by processes within the individual which significantly decrease the probability of survival.

The changes cannot be avoided or reversed; no one can escape the process of aging.

Differs from disease, which may be avoided, managed, or cured, in some cases.




## The Diversity of the Aging Process



**Individual Aging Process**

- Aging with lifelong disability & comorbidity
- Susceptibility to disease
- Social and cultural factors (e.g. quality of social network), family cohesiveness
- Compensatory behaviors + access to resources (e.g. healthcare).
- Gender
- Lifestyle
- Genetic profile
- Universal physical changes (sensory, reduced efficiency/capacity of organ systems, loss of muscle/bone mass)



## Types of Aging

**Primary Aging**

- Normal, disease free movement across adulthood
- Changes are inevitable


**Secondary Aging**

- Changes related to disease and poor health practices


**Tertiary Aging**

- Rapid losses in function shortly before death

(Birren & Cunningham, 1985)




## Physical Aging



Each body system has a **reserve capacity** (e.g. cardiovascular system, nervous system, digestive system, sensory system, musculoskeletal system etc..)

With increasing age – there is decline in the capacity/efficiency of cells/body systems. However, most of the time, the decline is not too noticeable.

Overall the body ages remarkably well – though some systems do decline quicker than others, and our lifestyle choices can greatly influence how we experience the aging process.



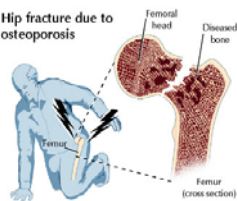

## Universal Physical Changes

**Osteopenia** - normal aging-related bone loss.

Osteoporosis “porous bones” – weak and brittle, greatly increases risk of fractures.

Caused by


- Reduction in estrogen (especially in post-menopausal women)
- Reduced calcium intake/absorption/reduced vitamin D
- Lack of exercise, heavy drinking, smoking, prolonged use of certain medications, (e.g. steroids, anti-anxiety, anti-depressants).

## Universal Physical Changes

**Osteopenia – extra caution for people with ASD**

- 1) Nutrition issues (eg. food sensitivities or intolerances, may result in inadequate levels of dietary calcium/vitamin D)
- 2) Lifelong use of medications to treat associated conditions (e.g. behavioral/mental health issues and epilepsy).



## Universal Physical Changes

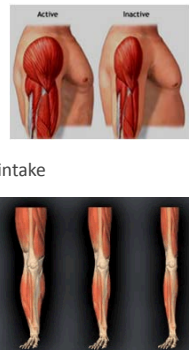

**Sarcopenia** – progressive loss of mass during adulthood.

Caused by:

- Slowing metabolism
- Reduction in testosterone/growth hormone
- Reduced protein intake/inadequate calorie intake
- Increasingly sedentary lifestyle

Results in:

- Loss of elasticity/flexibility
- Loss of muscle strength
- Efficiency of the heart is reduced
- Increase in slowness of movement/frailty


## Age-Related Changes in Vision

- Presbyopia: the lens of the eye loses becomes stiffer and less flexible – affecting the ability to focus on close objects




### Age-Related Changes in Vision

- Decline in sharpness of vision.
- Longer time required to focus on objects at different distances (e.g. looking at something in the distance, then reading a book).
- Decreased color discrimination due to yellowing of eye lens (be care with those who self-administer medications).
- Decrease in ability to adapt to changing levels of light (e.g. coming out of a movie theatre into the daylight).
- Decrease in ability to judge distances (depth perception).



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### Hearing Loss/Impairment

**Presbycusis** – aging related change in the ability to detect higher pitches – more noticeable in those age 50+.

When more severe – can interfere with understanding speech. Difficulty with sounds that are often found at the start or end of words e.g. the “st” in street, “ch” in church.


Illness, accidents, and cumulative exposure to environmental noise (loud music/headphones) are all possible factors that can lead to late onset hearing loss.

Note: Though mild hearing loss is equitable with the rates in the general population - **severe hearing impairment/loss/ is 10x higher in people with ASD (3.5%) compared with general population.**


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### Presbycusis

<http://www.freemosquitoringtones.org/>




Do you here what I hear?



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### Taste and Smell



**Gustation** (i.e. the sense of taste) decrements become more noticeable beyond 60+.

Decrease in taste receptors and increase in the stimulus threshold can result in food tasting blander with increasing age.


Often older adults may add more salt and sugar than used previously to compensate.

**Olfaction** (i.e. the sense of smell), decrements become more noticeable after age 70+.

Anosmia loss has also been associated with Alzheimer’s & Parkinson’s disease.

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### Touch



- **Somatosensory System** - detects external touch, but also responsible for experience of pain, temperature, pressure, and one’s awareness of one’s own body position.
- Reduction in sensitivity to pain, touch, temperature, and possible contributing factor to increased risk of falls.

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### Successful Aging

*Optimal Aging*


“A kind of utopia, namely, aging under development enhancing and age-friendly environmental conditions”  
(Baltes & Baltes, 1990).

*Successful Aging*

- Avoidance of disease and disability
- Maintaining mental and physical function
- Sustained engagement in social and productive activities  
(Rowe & Kahn,1997).


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### Modifiable versus Unmodifiable Factors for Successful Aging



**Unmodifiable**


- Age
- Gender
- Genetics
- Ethnicity



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### Modifiable versus Unmodifiable Factors for Successful Aging

**Modifiable**



- Eat a balanced and healthy diet (and supplements)
- Maintain a healthy weight
- Exercise on a regular basis (include weight bearing exercises)
- Manage stress / allow time for relaxation
- Don't smoke (and avoid secondary smoking!)
- Education (promote lifelong learning)
- Occupation (esp. promotes curiosity, or working with people)
- Leisure activities (mental, social, physical)
- Enriching relationships (evolving)
- Living in a nurturing/clean physical environment

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### Avoidance of Frailty!

Frailty is defined as the presence of 3 of the following 5 phenomena:

- involuntary weight loss,
- weakness, (e.g. poor grip strength)
- slow walking speed,
- self-reported exhaustion,
- low physical activity. (Fried et al., 2001).

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# Use it or Lose it!

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### Autism Spectrum Disorders (1 in 88)

2 cardinal characteristics

- Impairment in social-communication and interaction
- Restricted repetitive and stereotyped patterns of behavior, interests and activities.

~ 40% have Intellectual Disability  
 ~ 40% have Epilepsy  
 Overall, more common in males than females by 4.3 to 1 ratio.  
 However, without ID, ratio is 5.5 to 1.  
 With ID, ratio is 2 to 1.

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### Trajectory of Autism Symptoms Across the Lifespan

With regard to symptoms of autism there are 3 possible lifespan outcomes (e.g. Seltzer et al., 2004, Shattuck et al., 2007).

- Some individuals improve (abatement of symptoms)
- Some individuals plateau
- Some individuals lose skills (esp. associated with psychiatric disorders)

"Indeed, it is astonishing that as many as between 10 and 20% outgrow the diagnosis, as autism is arguably among the most severe and pervasive of the developmental disorders." (pg. 240, Seltzer et al., 2004)

"Behavior is not static, nor is how autism is in our lives static." (pg. 252, Bovee, 2000)

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## Where are the Older Adults with ASD?

Few studies include or target people aged 50+ with ASD

Who can we research - those with ASD dx known to formal support systems, those without formal ASD dx, but would meet researcher screening criteria for probable ASD.

Hidden population – never diagnosed, and never accessed formal support system – positive (exemplars of fully inclusive life), negative (over-reliance on a primary caregiver – future planning may be a concern).

The hidden population may give the most valuable insights to both the risk and protective factors to obtain an optimal quality of life and successful aging.

Perkins, E. A. & Berkman, K. A. (2012). *Into the Unknown: Aging with Autism Spectrum Disorders*. *American Journal On Intellectual and Developmental Disabilities*, 117, 478-496.



Special Issue on Aging and End Of Life, *American Journal on Intellectual and Developmental Disabilities (2012)*. Guest Editors Elizabeth Perkins & Sandra Friedman

## Life Expectancy and Causes of Death in People with ASD

Life expectancy reduced slightly compared with the general population - even among those with ASD, without severe physical disabilities, or who were non-ambulatory (Shavelle & Straus, 1998).

Scant research on disease prevalence rates.

Causes of death that are higher in ASD population compared with general population include:

- Seizures (SUD)
- Accidental Death (drowning, suffocation)
- Cardiovascular Disease
- Cancer
- Respiratory Disorders (mostly pneumonia)

(Shavelle et al., 2001; Mouridsen et al., 2008; Gillberg et al., 2010)

## Aging Persons with Autism

Recent study (Esbensen et al., 2009) noted that restrictive repetitive behaviors, i.e.

- restricted interests
- stereotypical movements
- need for rituals/sameness
- compulsive behaviors
- self-injurious behaviors

were *less severe* and *more infrequent* with increasing age.

## Are Reduction in Behavioral Symptoms Related to Aging of the Sensory Systems?

- Sensory seeking and sensory defensiveness (i.e. high and low thresholds for response to sensory stimuli, oral, tactile, auditory, and visual)
- With increasing age – there are changes in threshold levels in both directions to levels usual in the general population (i.e. hypersensitivity decreases and hyposensitivity increases) (Kern et al., 2006).
- Therefore previous triggers to sensory defensiveness and sensory seeking behaviors are no longer as salient.

## Dual Diagnosis

A study of aged 50+ adults with ASD, reported 31% met criteria for psychiatric caseness (Totsika et al., 2010).

However, in contrast, studies in children and adults with ASD report 70-75% (e.g. Ghaziuddin & Zafar, 2008; Simonoff et al., 2008).

Most common issues generally noted Anxiety Disorders, Depression, Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Tourette syndrome (e.g. Ghaziuddin & Zafar, 2008; Simonoff et al., 2008).

## Social and Vocational Outcomes

- Those with language skills, less impairment in social interaction, no ID, often fare better across lifespan in terms of education, employment, and social relationships, although still much lower rates of participation when compared to the general population (Howlin et al., 2004; Orsmond et al., 2004; Billstedt et al., 2005).
- Adults with ASD rely heavily upon their families in finding jobs, accommodations, and to utilize community facilities for social/recreational purposes (Howlin et al., 2004; Orsmond et al., 2004)

## Social and Vocational Outcomes

Participation in social and recreational activities are higher in those with:

- Less impairment in social skills
  - Increased functional independence
  - Greater maternal participation in activities
  - Greater number of supports services received
  - Inclusion in integrated settings during school years
- (Orsmond et al., 2004).

47%-56% report having no friends (Stuart-Hamilton & Morgan, 2011; Howlin et al., 2004)

*Emphasizes importance of lifelong learning, enriched environments, and community inclusion to optimize well-being over the lifespan.*

## Two Notable Examples of Older Adults with Autism Aging Successfully



Temple Grandin., PhD  
Age 65



Donald Gray Triplett  
Age 79

Leo Kanner's seminal paper published in 1943.  
Autistic Disturbances of Affective Contact  
*Nervous Child*, 2, 217-50.

## Vulnerability of Hidden Older Adults

64 year old with newly diagnosed ASD, lived independently, drove, and worked in a mail room of a department store for 20 years. Mother died (aged 101), he relocated to Florida to be near his siblings. Living in an ALF, developed late onset epilepsy and is no longer able to drive..... In a period of 12 months, he retired, lost his mother, his home, and driving license....

## Optimizing Successful Aging for Older Adults with Autism Spectrum Disorders

- ✓ Health promotion/health prevention - Wellness screenings (e.g. vision/hearing, dental checkups, cancer screenings, mammograms).
- ✓ Psychological well-being - advocate to ensure availability of optimal treatments/medications for those with dual diagnosis (e.g. anxiety, depression).
- ✓ Effective epilepsy management.
- ✓ Polypharmacy (careful monitoring with increasing age).

## Optimizing Successful Aging for Older Adults with Autism Spectrum Disorders

- ✓ Essential to promote lifelong learning, education, employment (retirement) and socialization opportunities – with increasing age.
- ✓ Emphasize lifelong physical activity, weight-bearing exercise, adapt activities rather than discontinue.
- ✓ Important to offer a range of new activities, that may result in continuing personal development and compensatory skill building.
- ✓ Retirement planning.
- ✓ Discuss future residential options/transition timeline.

## Adaptation to Aging, and Aging-Related Chronic Diseases

- Encourage discussion about aging and potential aging health issues to make individuals with ASD aware.
- Utilize opportunities for discussion when other family members and friends develop age-related chronic conditions.
- Lifestyle diet and activity changes/monitoring can be difficult but not impossible, and it is never too late to make beneficial changes!
- If individual self-administers or caregiver administer meds – do double check accuracy more regularly (may have switched to generic/changed pill style).
- Peer/caregiver modeling for self-management.



### Education for Lifelong Health Series

<http://flcic.fmh.usf.edu/program-areas/health.html> - free for download – click on the materials and resources tab from FCIC's health section.

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**“There are four kinds of people in the world:  
those who have been caregivers,  
those who currently are caregivers,  
those who will be caregivers,  
and those who will need caregivers.”**

Former First Lady Rosalynn Carter

~ 1 in 5 Americans are currently engaged in an informal caregiving role.

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### General Caregiving Research – An Overview

- Originally developed from concern of the challenges encountered by caregivers of people with Alzheimer’s disease.
- Highly stressed caregivers are at risk for poorer physical and psychological health outcomes.
- Time devoted to caregiving can also affect financial stability, employment opportunities, availability for other relationships.
- Caregivers can sometimes become captive to their caregiving roles (i.e. role captivity).

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### General Caregiving Research – An Overview

- Does have benefits, can reconnect or strengthen a relationship.
- Can be personally rewarding and boost self-esteem.
- Allows the care recipient to enjoy individualized attention in their home environment.

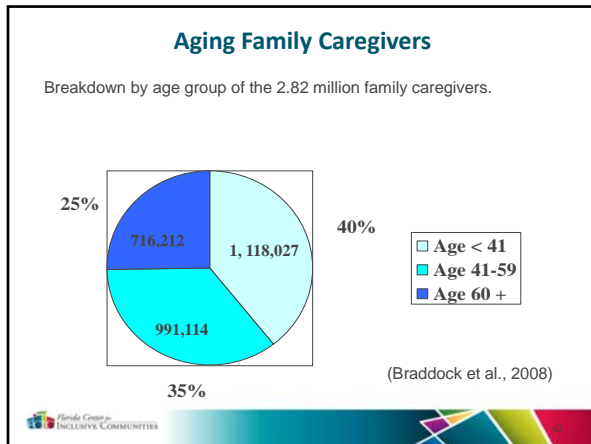
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### Importance of Family Caregivers

- Estimated 4.7 million people with ID (Including ASD) in 2008.
- 2.8 million live with their family caregivers.

Category	Percentage
Family caregiver	60%
Own Household	15%
With Spouse	13%
Residential Facility	12%

(Braddock et al., 2008).  
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### Where do people with IDD live?

Independent/family settings (88%)	Supervised Residential Setting (12%)
With Family Caregivers	Group Homes
Independent/Supported living	Intermediate Care Facilities/DD
With Spouse	Skilled Nursing Facilities
	State Institutions

(cited in Braddock et al., 2008., The State of the States in Developmental Disabilities).

### Aging Caregivers in Florida

There are ~ 60,000 caregivers aged 60+ who co-reside with their son/daughter with I/DD.

Only California has more aging caregivers!

(Braddock et al., 2008).

### Background

**Concerns**

1. Extensive duration of caregiving role
2. Health care concerns due to aging in care recipient/care giver
3. Fears about the long-term future of the care recipient

**Benefits**

1. Normative nature of parental caregiving
2. Expertise and feelings of mastery from long term caregiving

Haley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 1*, 24-30.

### Case Study – Compound Caregiver

- Parent caregivers of adults with ID may actually undertake this role for the entirety of their own lifetime.
- Likelihood of becoming a sandwich caregiver (i.e. caregiving for an older parent) is also increasing (Rogerson & Kim, 2005).
- There is also the possibility that these primary caregivers may also undertake additional caregiving duties to other family members (e.g. in-laws, spouse, and siblings).
- Case study that described a mother of an adult son with Down syndrome, who became a caregiver to other family members on 4 occasions.

Perkins, E. A. (2010). The compound caregiver: A case study of multiple caregiving roles. *Clinical Gerontologist, 33*, 248-254.

### Caregiver Study

- 1) How common is compound caregiving?
- 2) Does compound caregiving status impact physical and mental well-being of compound caregivers compared with non-compound caregivers?

Perkins, E. A. & Haley, W. E. (2010). Compound caregiving: when lifelong caregivers undertake additional caregiving roles. *Rehabilitation Psychology, 55*, 409-417.



## Caregiver Study

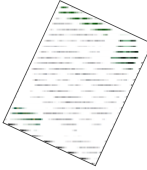

Cross-sectional, primary data collection

Sample N = 91 parental caregivers

Aged 50+ with co-residing son/daughter with ID aged 18+

Convenience sample drawn from various agencies, website recruitment, and parent-to-parent referral

Caregivers from various states participated:  
 Florida (78), New Jersey (5), Georgia (4), Nevada (1), Maryland (1), Oklahoma (1) South Dakota (1).


## Compound Caregiver Variables

Compound Caregiver Status.

*Do you currently have any other caregiving responsibilities to another family member other than your son/daughter with ID?*


Relationship to the compound care recipient.

Major health issue that prompted caregiving duties.




	Mean or %	SD	Range
<b>Caregiver Characteristics</b>			
<i>Demographic</i>			
Age (years)	60.8	8.5	50 – 92
Education (years)	15.1	2.4	12 – 22
Gender (Female)	91%		
Race/Ethnicity (White)	92%		
Household Income (>\$50,000)	78%		
<i>Health</i>			
Total Comorbidities	5.1	2.9	0 – 13
Comorbidity Interference	9.2	7.9	0 – 35
<i>Caregiving</i>			
Total caregiving hours per week	39.4	21.3	7 – 88
Compound Caregiver Now (Yes)	37%		
Compound Caregiver Ever (Yes)	68%		
Anticipated Future Caregiving (Yes)	34%		
Duration of compound caregiving (months)	36 *		

\* Median



	Compound Caregiver		Non-Compound Caregiver		t
	M	SD	M	SD	
<b>Caregiver Characteristics</b>					
<i>Demographic</i>					
Age (years)	58.8	7.9	61.1	8.9	1.22
Education	14.7	2.29	15.4	2.53	1.26
<i>Health and Caregiving</i>					
Total Comorbidities	4.79	2.96	5.42	3.01	.97
Comorbidity Interference	8.68	8.66	9.52	7.47	.494
Total Caregiving Hours	38.66	20.82	39.84	21.89	.253
<b>Caregiving Hours + CCG<sup>a</sup> hours</b>	<b>51.60</b>	<b>26.34</b>	<b>39.84</b>	<b>21.88</b>	<b>-2.30*</b>


<sup>a</sup>CCG = Compound caregiving \* p < .05 (2-tailed).



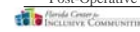
### Caregivers (57) and Compound Caregivers (34)

	Compound Caregiver		Non-Compound Caregiver		t
	M	SD	M	SD	
Life Satisfaction	17.05	5.81	17.58	7.03	.36
Depression	10.94	9.30	12.61	9.65	.85
Physical Health	44.51	11.28	43.09	10.07	-.62
Mental Health	47.66	11.22	48.67	11.53	.41
<b>Desire to Place</b>	<b>3.61</b>	<b>1.72</b>	<b>2.49</b>	<b>1.63</b>	<b>-3.11*</b>

\* p < .01 (2-tailed).



Relationship	N	%
Mother	13	(38.2%)
Father	4	(11.8%)
Spouse	4	(11.8%)
Sibling	3	(8.8%)
Aunt/Uncle	3	(8.8%)
2 <sup>nd</sup> Child with Intellectual Disability	3	(8.8%)
Mother in Law	2	(5.85%)
Grandchild with Medical Needs	1	(2.9%)
<b>Major Health Issue</b>		
Alzheimer's Disease	7	(20.6%)
Elderly Frail	4	(11.8%)
Advanced Macular Degeneration	4	(11.8%)
Cardiovascular Disease	4	(11.8%)
Intellectual Disability	4	(11.8%)
Parkinson's Disease	2	(5.9%)
Cancer	2	(5.9%)
Chronic Mental Disorder	2	(5.9%)
Hip Fracture/Replacement	2	(5.9%)
Stroke	1	(2.9%)
Diabetes	1	(2.9%)
Post-Operative Convalescence	1	(2.9%)



## Compound Caregivers



**Compound Caregivers:  
Overlooked and Overburdened**  
A White Paper  
Elizabeth A. Perkins, Ph.D. & Nancy  
Haley, Ph.D.

- Released in 2011
- Based upon previous research articles
- Highlights difficulties and relative frequency of being a “compound caregiver”
- Aims to raise awareness of this issue and offer state/federal solutions

[http://flfcic.fmhi.usf.edu/docs/FCIC\\_CompoundCaregivers\\_070811.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_CompoundCaregivers_070811.pdf)

## Reciprocity


- Relationships between caregivers and their care recipients are complex.
- Reciprocity exists these relationships.
- Recent study highlighted that in a group of aging caregivers (N=91), 25% reporting giving more than they received emotionally, and 22% reported that they received more help than given in help around the home.
- Co-dependency may increase as the caregiver ages.  
(Perkins & Haley, in press)

## How can we support caregivers?

- **Utilize and embrace** the unique knowledge and expertise the caregiver has.
- **Promote collaboration and discussion** of caregiving issues with all family members (e.g. siblings) to encourage fair distribution of caregiving duties.
- **Encourage use of available services** and options (e.g. home help, companion services).
- **Encourage building/strengthening of informal network** – friends, other parents/caregivers, local community resources, online communities.
- **Imperative to encourage caregivers to make future plans**

## How can we support caregivers?

- **Encourage caregivers to participate in family/parent or caregiver support groups** including online communities.
- **Use respite care, and encourage “me” time** – a regularly scheduled activity that the caregiver truly enjoys.
- **Encourage caregivers to be more aware of their health, and stress**, and not neglect or overlook their own healthcare needs.



**Future Care Planning:  
A Roadmap for  
Family Caregivers**  
Arizona University Center of Excellence in Developmental Disabilities  
Education, Research, and Service (UCEDS)  
University of Central Florida (UCF)

Don't Delay.....

Start to make those plans.....

What if's  
Who with  
Where  
Finances

[http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/CAREGIVING\\_Roadmap\\_021010.pdf](http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/CAREGIVING_Roadmap_021010.pdf)

## The Future is Now!

**The Future is Now: A Future Planning Training Curriculum for Families and Their Adult Relatives with Developmental Disabilities.** Factor, A., Debrine, E., Caldwell, J., Arnold, K., Kramer, J., Nelis, T., & Heller, T. (2010). 3<sup>rd</sup> Edition

This curriculum helps families to plan and prepare a letter of intent that lays out their dreams for the future and identifies the steps required to transform this dream into a reality.

<http://www.rtcadd.org/blog/files/c640b98a22c0251fd9d4ea8f1e8f615b-5.html>

## Easing Your Stress Guide

Free booklet by the Florida Developmental Disabilities Council

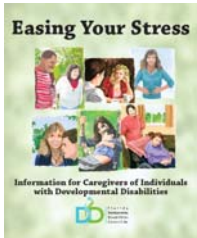
Aimed specifically at caregivers of people with developmental disabilities.

Includes description of stress, and guidelines on how to ease stress.

**"Be positively selfish by doing things for yourself."**

**Remember: Stress is a reaction to an event rather than the event itself."**

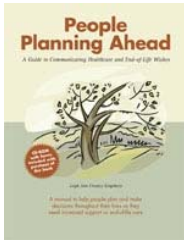
<http://www.fddc.org/sites/default/files/Easing%20Your%20Stress%20English%206-3-2013%20web.pdf>



**Easing Your Stress**  
Information for Caregivers of Individuals with Developmental Disabilities

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## Planning for End-of-Life Care



**People Planning Ahead**  
A Guide to Communicating Preferences and End-of-Life Wishes

Documents the wishes of an individual and their caregivers with respect to healthcare and End-of-Life wishes.

Available from the American Association on Intellectual and Developmental Disabilities

<http://aidd.org/publications/bookstore-home/product-listing/2013/06/24/people-planning-ahead-communicating-healthcare-and-end-of-life-wishes>

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## Win Hammer - Artist



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## Promoting Effective Communication to Health Care Providers

- An individual with ASD and/or their caregiver may inadvertently forget to share important information.
- An individual may be accompanied by a member of staff who does not know them well.
- In any health care setting (but esp. in an emergency/acute health episode)– health care professionals who are unfamiliar in providing care to those with special needs, coupled with unprepared individuals/caregivers may lead to poor clinical evaluation, poor patient/health care professional interaction, and ultimately inappropriate treatment..

**effective communication is the key!**


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## My Health Passport

- Not just another form....
- Designed to be eye-catching, provide information that is useful
- Needed to be comprehensively concise ☺
- Provide health care providers with information and strategies to modify the environment, or their own behavior
- Appropriate for all ages
- Makes the unfamiliar become familiar!

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## My Health Passport



**My Health Passport**

**PLEASE READ THIS** before you try to help me with my care or treatment.

If you are a health care professional who will be helping me, please read this before you try to help me with my care or treatment.

My full name is: \_\_\_\_\_  
 I like to be called: \_\_\_\_\_  
 Date of birth: / / \_\_\_\_\_  
 My primary care physician: \_\_\_\_\_  
 Physician's phone number: \_\_\_\_\_

Attach your picture here!

This passport has important information so you can better support me when I'm in your hospital or clinic.  
 Please keep this with my other notes, and where it may be easily referenced.

My signature: \_\_\_\_\_ Date completed: / / \_\_\_\_\_  
 You can talk to this person about my health: \_\_\_\_\_  
 Phone number: \_\_\_\_\_ Relationship: \_\_\_\_\_

I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, also state if extra time/support is needed)

After the demographic information

...notice that the first thing that is emphasized is how does the person **communicate** here!

Does the person avoid eye-contact but attends to everything that is said?  
 -Do they make idiosyncratic sounds that have a consistent meaning – e.g. Are they able to verbalize yes and no clearly – “e.g. do they make “eee” sound for yes?”

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Florida Center for Inclusive Communities

**My brief medical history:** (include other conditions in.g. visual impairment, hearing impairment, diabetes, epilepsy, past operations, illnesses, and other medical issues)

**My current medications are:**

**When I take my medication, I prefer to take it:** (e.g. with water, with food)

**I am allergic to:** (for medications or foods, e.g. penicillin, peanuts)

**If I am in pain, I show it by:** (plus how I have a low/high pain tolerance)

**If I get upset or distressed, the best way you can help is by:** (e.g. play my favorite music)

Brief history, medications, allergies: all important to document.

How a person prefers to take medications: established routines to be adhered to, food /drink preferences

Pain/Distress:

-health care professionals might be particularly apprehensive when presented with an individual in pain/distress with intellectual disability.  
 - we all experience pain differently, does an individual understand a numeric or picture pain scale.  
 - when distressed, is there an effective way to can usually allay their fears, comfort them?

**How I cope with medical procedures:** (e.g. how I usually react to needles, IV's, physical examinations or eye, ear/nose/throat-what have procedures never experienced before or in recent years)

**My mobility needs are:** (e.g. whether I can transfer independently, devices I use, pressure relief needed)

**When getting washed and dressed, you may assist me by:**

**When drinking, you may assist me by:**

**When eating, you may assist me by:**

How I cope with medical procedures:

-Taking a blood pressure can be a relatively novel experience.

Mobility/personal care needs: helps people from "over-assisting", from lack of knowledge.

Eating/drinking: -individuals may have needs that are easily accommodated if only they are shared. .e.g. only drinks from a particular cup, only likes to eat from a bowl, does not use a knife!

**My favorite foods and drinks are:**

**I do not like to eat or drink the following:**

**I am very sensitive to:** (specific sights, sounds, odors, textures/tastes, etc. that really bother, e.g. fluorescent lights, fluorescent, bleach, or hairbrush)

**Things I like to do that will help pass the time:**

**How to make future/follow-up appointments easier for me:** (e.g. give me the initial appointment of the day, allow extra time for the appointment, let me visit before my appointment, give information to my caregiver, etc.)

Food/drink: Food /drink refusal may occur from restricted range of drinks/foods that are tolerated. Certain textures (e.g. jello), odors from certain foods, presentation of unfamiliar food, may contribute to difficulties at meal-times. Food/fluid intake is crucial, so availability of alternative choices is critical.

Hypersensitivities can also be problematic, given clinical environments (e.g. the odor from alcohol swabs), tv's/music if in a shared room/open ward.

Follow-up appointments: Request early /late times, pre-examination orientation visits to new clinics/offices. Pictures of the medical/nursing staff that will be seeing the person.

### Endorsement from a local provider!

The Health Passport is distributed by the Child Life Department in inpatient and outpatient areas following assessment of the child soon after admission. During the time of distribution of this resource, we inform families to present the passport upon future admissions. Our staff has been educated on this resource and to consult the Child Life team when a family presents with the Health Passport so that a copy can be made and put on the front of the patient's chart.

Having this resource available has increased communication within the interdisciplinary team and has allowed staff to take into consideration the specific needs of the child—medically, emotionally, and psychosocially—and alter the hospital environment to meet the child's needs.

It is also beneficial to our families who are "frequent flyers" so that they do not have to repeat information to different physicians and nurses, therefore allowing them to focus on the needs of their child in this sometimes chaotic and unfamiliar environment. Thank you so much for providing us with this resource!"

**Leslie Dempsey, Child Life Specialist, St. Joseph's Children's Hospital - Tampa.**

## My Health Passport

Print and/or save file directly from FCIC's website:  
[http://flfcic.fmhi.usf.edu/docs/FCIC\\_Health\\_Passport\\_Form\\_Typeable\\_English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf)

[http://flfcic.fmhi.usf.edu/docs/FCIC\\_Health\\_Passport\\_Form\\_Typeable\\_Spanish.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_Spanish.pdf)

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*If you would like reprints of further information about of any my publications (bold in the reference list), please do not hesitate to email me!*

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