



**Department of Developmental Services  
Office of Quality Management**

**Living Well  
SPRING/SUMMER 2012**

Department of Developmental Services  
Office of Quality Management

# Living WELL

*Spring/Summer2012*

*Welcome to the Spring/Summer 2012 issue of "Living Well", a publication of the Department of Developmental Services, Office of Quality Management. "Living Well" is published on a semi-annual basis and features important information for individuals and their supporters.*

*In this edition, you will find helpful information to assist people you support to enjoy spring and summer activities in a safe and healthy manner.*

*"Living Well" represents one component of DDS's continuing commitment to share information which will safeguard and improve individuals' quality of life. Information and knowledge is a powerful tool. We hope that this and future editions of "Living Well" will be used effectively to enhance the health and well-being of individuals we support.*

*We'd welcome your feedback and suggestions regarding content areas for future editions of the publication. Please submit your suggestions to [Sharon.Oxx@state.ma.us](mailto:Sharon.Oxx@state.ma.us). Thank you!*

*Elin Howe*

*Commissioner Department of Developmental Services*

# ***DID YOU KNOW?***

## **Aging in the I/DD population**

Just like the rest of their counterparts in the “baby boomer generation” people with intellectual and developmental disabilities are developing health issues as they age. In addition to their lifelong health issues, the people we care for are now faced with additional common ailments of aging: osteoporosis, arthritis, hearing loss, vision issues, circulation problems, heart/lung diseases and memory disorders, such as dementia and Alzheimer’s Disease.

Alzheimer’s disease is fairly common among older adults and is a higher risk for anyone with an intellectual disability, especially those with Down Syndrome. It is often seen at a much younger age in individuals with Down Syndrome. In 1920 a child born with Down’s syndrome had a life expectancy of less than ten (10) years. Now, according to the Alzheimer’s Association, the average life expectancy is 56 years. At age 40 a person with Down’s syndrome has a 25% chance of having Alzheimer’s disease, increasing to 66% over the age 60.

With the improvement of medical care, all persons with intellectual and developmental disabilities are living much longer, bringing new challenges as they age. Life expectancy for this population has doubled in the past few decades.

## **SO WHAT DOES THIS MEAN FOR YOU AS A CAREGIVER?**

The aging adult with any intellectual or developmental disability will be expected to have more physical and mental health issues related to aging that may affect their activities of daily living, mobility and functional well-being. You may notice changes in their activities, behavior, mood, previously learned skills, memory, language and personality. You may notice changes in their eating, sleeping patterns, changes in their socialization (less outgoing, more isolated), changes in their language skills (trying to find words, speaking in phrases).

## **SO WHAT CAN YOU DO?**

Observe and report any behavioral, social, functional changes or loss of skills, language and memory changes to your supervisor or the health care provider. Monitor and document all changes in health and function on a routine basis and review periodically. Keep the health care record up-to-date and keep all appointments for health care provider visits and testing. Communicate your observations with health care providers and advocate for additional medical evaluations. The information you can collect will be invaluable to the health care provider, so every detail is important. The *Dementia/Alzheimer Disease Screening Tool* included in this newsletter can be used to track such changes.

# Massachusetts Department of Developmental Services

## Dementia Screening Tool for Direct Care Professionals

This assessment tool is designed to identify early changes that could signal the onset of dementia. The checklist should be completed at least twice a year and is especially important for individuals over the age of 35 with Down Syndrome. Change may indicate a need for a further medical/nursing assessment. Please notify your area office nurse and the individual's service coordinator if you notice any changes.

**Individual:** \_\_\_\_\_ **D.O.B.** \_\_\_\_\_

**Down Syndrome:** Yes  No

**Code: A = always B = usually C = rarely D = never; or circle Yes or No where indicated.**

<b>Mental Status</b>	<b>Review : Baseline</b>	<b>2</b>	<b>3</b>	<b>4</b>
Alert				
Naps during the day				
Awake at night				
Can start activities or social contact without help independently				
Becomes easily discouraged				
Forgetful				
Combative/ hits				
Cries easily				
Fearful				
Knows day of week & time of day				
Talks to self				
Recognizes familiar people				
Prepares for leisure activities				
Change in regular routine/behaviors				

<b>Day/Work</b>	<b>Review : Baseline</b>	<b>2</b>	<b>3</b>	<b>4</b>
Attends day/work program as scheduled				
Able to complete day/work routines				
Day/Work results are consistent				
Maintains energy for entire day				
Stays focused on tasks				

<b>Seizures</b>	<b>Review: Baseline</b>	<b>2</b>	<b>3</b>	<b>4</b>
History of seizures	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>
Takes seizure medications	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>
Has Dilantin been started in past year for seizures	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>
Seizure activity noted (not seen before)	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>
Increase/change in seizure activity	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>	<b>Yes No</b>

## Dementia Screening Tool for Direct Care Professionals

<b>Communication</b>	Review :	Baseline	2	3	4
Speaks in full sentences or phrases (N/A if always non-verbal)					
Writes name, reads, able to do arithmetic (N/A if never able)					
Difficulty in finding words					
Using self-talk again					
Indicates needs and wants					
Follows simple directions					

<b>Mobility</b>	Review :	Baseline	2	3	4
Moves through home without help					
Walks up and down stairs alone					
Walks with assistance					
Gets up from chair independently					
Loses way in familiar setting					
Change in walking behavior					

<b>Eating</b>	Review :	Baseline	2	3	4
Eats independently					
Uses utensils and napkin correctly					
Uses cup correctly					
Chews properly					
Swallows without problems					
Current Weight					

<b>Toileting/ADL</b>	Review :	Baseline	2	3	4
Independent/indicates need to toilet					
Incontinence of urine					
Incontinence of feces					
Change in Personal Care routine					
Fearful/refusing to bathe					
Needs help with things used to be able to do					

Review 1 Agency/Reviewer: \_\_\_\_\_ Date: \_\_\_\_\_

Review 2 Agency/Reviewer: _____ Date: _____
---

Review 3 Agency/Reviewer: \_\_\_\_\_ Date: \_\_\_\_\_

Review 4 Agency/Reviewer: \_\_\_\_\_ Date: \_\_\_\_\_

## **IMPORTANT REMINDER!!**

Some of the individuals you support may put objects in or near their mouth and swallow them. This behavior is often referred to as Pica, which means swallowing non food items, This is a very serious health issue that is more common among people with developmental disabilities. In some cases the individual may be known to exhibit pica behavior but in others staff may report no active history of such behavior. Whether someone carries a diagnosis of pica or not, there are some behaviors we should all be alert to around an individual's risk for ingesting inedible and thus, indigestible, objects. One outstanding indicator is whether or not they put particular objects in or near their mouth. The risk of swallowing such items is certainly high and these items should be kept out of reach. Being vigilant about potential objects within close proximity and conducting frequent environmental sweeps to remove those objects can help assure a safe living and working environment for the individual.

Any behavior where an individual regularly puts objects in or near their mouth should prompt the need for an individualized pica protocol. For more information on Pica or on managing pica copy of the Massachusetts DDS Pica protocol and management plan guidelines can be found by going to:

<http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/provider-support/health-promotion/risk-management.html>

Inform your supervisor and/or nurse if you suspect that an individual you work with is at risk for swallowing nonfood items or you think may have swallowed a nonfood item. The earlier help is sought, the better the outcome.



# HEAT ILLNESSES

- **Heat Cramps** occur after vigorous activities like running or playing tennis. Their signs are painful abdominal spasms and cramps in major muscles such as the legs and abdomen. Cramps subside with rest, cooling down and plenty of water.
- **Heat Exhaustion** has many symptoms-fever, heavy sweating, fainting, rapid pulse, low blood pressure, clammy skin, ashen skin tone and nausea. Over exertion and not drinking enough water is the usual cause. To treat it, go indoors with a fan or air conditioning or to a shady spot, apply cool clothes, immediately lie down with your legs elevated, loosen tight clothes, and drink cool water or sports beverages.
- **Heat Stroke (Sunstroke)** can be life-threatening and requires immediate medical help. The symptoms include not only those associated with heat exhaustion, but also very rapid pulse and breathing, delirium, unconsciousness, and lack of perspiration to cool the body.

## **Risk factors for heat stroke include:**

- Dehydration
- Age over 65
- Obesity
- Consuming alcohol in hot weather
- Having chronic heart or lung disease
- Taking medications that interfere with the body's heat-regulating system

## **To prevent a heat illness**

- *Avoid direct sun from late morning until 4pm*
- *Limit vigorous exercise or chores to early morning or late afternoon*
- *Dress in light colored, loose-fitting clothes*
- *Continually drink plenty of water or juice*
- *Avoid caffeine or alcohol*
- *Eat light meals*

## **SUN EXPOSURE**

***Whenever you or the people you support are in the sun, you need to apply sunscreen. Buy a quality product rated at least SPF (Sun Protection Factor) 30 and apply it liberally to all exposed skin at least 30-60 minutes before going out into the sun and frequently thereafter especially during peak sun hours or after sweating or swimming.*** Not only will this help prevent sunburn but skin cancer as well.



Too much sun is also a risk factor for cataracts, so use sunglasses that block UVA and UVB ultraviolet rays. And don't forget your wide brimmed hat.

## **Remember,**

**Certain medications (like anticonvulsants, antipsychotics and high blood pressure medications) can cause people to burn more rapidly and more severely.**

# DEHYDRATION

(The lack of sufficient fluid in the body)

Because many people are on certain medications requiring a stable blood level to maintain effectiveness (like seizure and psychotropic medications), even mild dehydration can cause those blood levels to rise to dangerous levels, even toxic levels. This can create serious health consequences for the individual. Increasing fluid intake on hot days and offering them frequently can help prevent such an event.

Some signs of dehydration include:

- Decreased amount of urine
- Less frequent urination
- Dry skin or cracked lips
- Sunken eyes
- Less elasticity to the skin
- Fever
- Sleepiness
- Headache
- Increased heart rate
- Strong, dark urine



## **REMEMBER:**

*Popsicles, watermelon, cantaloupe, fruit salad and jello all contain a lot of water and summertime is the perfect time to indulge in such treats.*

As many of the individuals supported by staff may not be able to express their increased need for fluids or are unable to access it independently, special effort must be made to anticipate this need by staff.

## **RULE OF THUMB:**

**If a staff person is consuming a beverage, the person that they support should have one as well.**

# WATER SAFETY

Enjoying the water can be a special way to enjoy warm, summer days. With some precautions and planning as outlined below, these activities can be the basis of happy memories of a fun summer.

- Assess each individual's capabilities and needs when using different water venues, such as a pool, the ocean, or boating. Ensure staff is knowledgeable of people's capabilities and staff has water safety skills to support individuals while enjoying water activities.
- Know each individual's vulnerabilities and provide ongoing supervision to ensure everyone's safety. Remember, in sight supervision must be provided at all times to fully ensure safety.
- Before use, identify and utilize other available resources to ensure safety such as Lifeguard over sight of the beach or pool
- Before use, identify any potential hazards and unique safeguards required for the specific water environments individuals will be using. Potential hazards, for example, could include finding out about surf conditions to determine whether swimming in the ocean is safe, or knowing the depth of the water or possible underwater hazards when swimming at a lake or river. Safeguards would include the use of life jackets when boating.
- Watch out for the "dangerous too's"—too tired, too cold, too far from safety, too much sun, too much strenuous activity.
- Pay attention to the weather and stop swimming at the first indication of bad weather. Know what to do in an electrical storm. Upon the first sign of thunder or lightning, leave the water, and do not re-enter the water until at least twenty minutes after the last indication that a storm is present.
- For pools at individuals' homes, ensure that the pool is maintained safely and that safeguards are in place when the pool is temporarily or seasonally not in use. For more information, refer to the DDS's "Safeguards for Pools" issued on 1/8/97.
- Even wading pools can pose a danger. Make sure the surfaces are not slippery as people step into the pool. Apply nonskid bathtub decals to reduce this risk. Ensure that individuals are well-supervised when using the pool, and empty the wading pools when not in use.



## **CREEPY CRAWLEES and OTHER PESTS**

- **Bee, wasp or hornet stings** can cause a medical emergency if one is allergic to them. You should be aware of those you are responsible for who have this problem and make sure you know what to do if they get stung. Most people, however, only experience a sharp pain that goes away after a few minutes. It is important to remove the stinger promptly: use a flat edge such as a credit card to scrape it from the welt, Wash the area and apply ice. Continue to monitor for signs of infection or increased inflammation.
- **Deer ticks** are tiny insects that live in low brush and can spread Lyme disease in a small percentage of the people they bite. ***Use bug repellent with DEET whenever out in such areas to keep these pests and others away.*** Wear a long-sleeved shirt, long pants, socks and a hat if you are in tick country. When you get home, carefully check yourself and the person you support for ticks. And don't panic! Generally, a Lyme disease carrying tick usually has to be attached for at least 24 hours to spread the disease. Ticks can be difficult to kill so it is best to flush them whenever possible.
- **Mosquitoes:** Avoid outdoor activities at dusk or dawn. That is when they are most active. Use a mosquito repellent. Most repellents are effective for many hours so there is no need to keep reapplying it. Wash it off carefully after going back inside. Wear light-colored clothing as mosquitoes are attracted to dark or bright colors.



If you would like further information on these topics or others, we suggest you visit the following website:

[www.state.ma.us/dph](http://www.state.ma.us/dph)

### **MAP Reminder:**

A HCP order is **Not** needed for the use of  
**Bug Spray**  
**or**  
**Sunscreen**

# **West Nile Virus**

*(And we don't live anywhere near the Nile)*

## **So what is it?**

West Nile Virus (WNV) was first diagnosed in New York City in 1999. This potentially fatal disease has spread across the country more quickly than expected. Its continued spread means that it is here to stay. Last year Massachusetts had 23 cases reported and 3 deaths.

## **How do I get it?**

WNV is principally a disease of birds. It grows inside an infected bird and is spread to other birds, animals and people through mosquito bites. Not all species of mosquitoes carry the disease. Even in areas where mosquitoes carry the disease, much less than 1% of the insects are infected.

Although adults are more likely to be bitten by mosquitoes than children and men are bitten more often than women, anyone can become infected with WNV. The disease cannot be spread through normal contact with infected animals or people.

## **What are the symptoms?**

Most infected people will not know that they have the disease because they will have either very mild symptoms or no symptoms at all.

### **The symptoms may include:**

- **Fever**
- **Headache**
- **Body aches**
- **Skin rash (rare)**
- **Swollen lymph nodes (rare)**

The symptoms usually occur within a few days to a couple of weeks after infection. Persons who have flu-like symptoms that continue for more than 2-3 days should contact their physician immediately. If a mild infection exists, fluids and rest will be prescribed. Those who have symptoms of a more severe infection will be given a blood test to see if there are antibodies to the virus present.

## **What if I have a severe case?**

Because so specific treatment currently exists, people who develop a severe infection are hospitalized to receive supportive care to help their bodies fight the disease. That care might include intravenous fluids, respiratory support, and prevention of other infections which can weaken the body's ability to fight the WNV. Most people fully recover from WNV.

## **So what can I do to prevent it?**

There are several things you can do to lower the risk of WNV by lowering the risk of mosquito bites:

- **Remove all open containers of water and fill all pools of standing water near your home**
- **Stay indoors at times when mosquitoes are most active-dawn, dusk, and early evening**
- **When outdoors, wear long-sleeved shirts and long pants**
- **Be on the lookout for dead birds, especially crows and jays, and report them to local and state authorities**
- **Avoid floral-scented perfumes and toiletries, such as soaps, lotions and shampoos**
- **Spray clothing with insect repellent that contains 35%-50% DEET. Use repellent sparingly on exposed skin, and follow manufacturer's instructions**

- **Vitamin B and ultrasonic devices are not effective against mosquitoes**

The risk from WNV is real but extremely low. By taking a few precautions and being aware of the WNV symptoms, you'll be ready to enjoy all of the pleasures of summer.



# Picnic Checklist

As you head out this summer to enjoy the warm weather and outdoor activities, here is a checklist to help you make sure you have everything you need to make it a safe outing for you and those you support.

<input type="checkbox"/> Sunscreen (SPF 30 or greater)	<input type="checkbox"/> Bug spray
<input type="checkbox"/> Plenty of water or caffeine-free beverages	<input type="checkbox"/> Fully charged cell phone for emergencies
<input type="checkbox"/> Lightweight clothing to cover up if very sunny	<input type="checkbox"/> Emergency fact sheets for all individuals
<input type="checkbox"/> Epipens (if ordered for anyone allergic to insects or food)	<input type="checkbox"/> Lots of ice and coolers to keep cold foods cold
<input type="checkbox"/> First aid kit	<input type="checkbox"/> Hats to protect from the sun
<input type="checkbox"/> Equipment to allow food to be prepared to correct consistency (if applicable)	<input type="checkbox"/> Food that can be safely maintained in hot weather (to prevent food poisoning)
<input type="checkbox"/> Plenty of gas	<input type="checkbox"/> Enough staff to assure safety
<input type="checkbox"/> Portable ramp for access (if applicable)	<input type="checkbox"/> Adapted utensils (if applicable)
<input type="checkbox"/> Information about site you will be visiting ( directions, bathroom access, parking, wc access, etc.)	<input type="checkbox"/> Change of clothes for swimmers or those with toileting issues
<input type="checkbox"/> Towels if swimming planned	<input type="checkbox"/> Blankets and chairs for seating

