

Setting the Standard for Nutrition in Behavioral Healthcare

Addressing Dementia and Alzheimer's Disease in a Community Based Organization Serving Individuals with Developmental Disabilities with a Focus on Nutrition

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MS, RD, CDN

Alzheimer's disease (AD) is the most common cause of dementia, among older people. This decline in cognition is not a normal part of aging. In most people with AD, symptoms first appear after age sixty (1). AD is the result of the formation

of plaques and tangles in the brain that causes the gradual loss of connections between nerve cells (neurons) in the brain. This loss leads to diminished cell function and cell death. As nerve cells die throughout the brain, affected regions begin to shrink. By the final stage of AD, damage is widespread, and brain tissue has shrunk significantly. This process starts in a region of the brain that affects recent memory, and then gradually spreads to other parts of the brain. Although treatment can slow the progression of AD and help manage its symptoms in some people, there is currently no cure for this disease (2,3).

People with Down syndrome (DS) develop a clinical syndrome of dementia similar to that of individuals without DS. The main clinical difference is the early age of onset of AD in individuals with DS, with symptoms present in their late 40s or early 50s. Studies show that there may be differences unique to persons with DS. One study compared the clinical findings of persons with dementia and DS with those of persons with dementia and intellectual disabilities due to other etiologies. Those with DS had a higher prevalence of mood changes, over-activity, auditory hallucinations, disturbed sleep, but

less aggression. The neuropathology of AD in persons with DS closely resembles that of AD in individuals without DS. However, even though conclusions from research studies may be interchangeable, the AD in persons with DS should be considered a different entity than the AD in persons without DS (4).

Research and clinical evidence suggest that the incidence of AD for people with Down syndrome (DS) may be the same or greater than the general population. Not all individuals with DS will develop AD and not all individuals with the diagnoses of IDD and AD have DS. Those showing Alzheimer's-type symptoms may not have AD. Other conditions can mimic symptoms, such as drug interactions, and must be considered before a diagnosis of dementia is made (5). It is estimated that of individuals with DS who are over age 35, twenty-five percent or more show clinical signs and symptoms of Alzheimer's-type dementia. The percentage increases with age. In the general population, AD does not usually develop before age 50, and the highest incidence (in people over age 65) is between five and 10 percent. The incidence of AD in the DS population is estimated to be three to five times greater (6).


Organization's Activities

To address the needs associated with the aging of our service population, the Schenectady ARC had convened a committee of clinicians, support staff and others in early 2008. The agency's "Aging Committee" addressed facility needs such as accessibility in the residential homes and day programs, caregiver supports, nutrition and other health related needs. Through various surveys (for consumers, their families, and program staff) we found that we needed to

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Submissions: Articles about successful programs, research, interventions and treatments, meeting announcements and educational program information are welcome and should be forwarded to the editor by the next deadline.

Future Submission Deadlines

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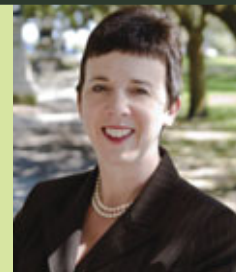
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From the Chair

Charlotte Caperton-Kilburn, MS, RD, CSSD, LDN



It is hard to believe how time flies when you are working hard. This is my final letter as BHN Chair. I would like to say "thank you" to all the BHN officers for their support and help during this year. To the members of BHN, please continue to share your thoughts about the needs of this DPG so that plans can be made for your benefit.

Several projects are at hand at this writing. Many of our publications will be updated over the next year. We are currently looking for those with specialty in each of the BHN areas who would be willing to work with the resource professionals and the publications team to make these updates. Please email me at nflperformance@yahoo.com if you are interested or want to know more.

Therese Shumaker, Chair-Elect, would love to have you contact her if you are interested in serving on the BHN BOD 2012-2013, shumaker.therese@mayo.edu. Several positions will be available on the BOD next year, but the most immediate need is for a webinar coordinator. Let me know if this is of interest to you.

I hope that each of you were able to attend our webinar Twitter 101 on February 27th, presented free to BHN members. It is our desire to provide high quality products and services for members, by members. If you have a hot topic to share with our DPG through a webinar presentation (stipend provided), we want to hear from you.

It has truly been a year of much hard work in our DPG and much accomplished. It has been a privilege and an opportunity for building life-long relationships in the dietetics profession and the practice of behavioral health nutrition. I hope there are members who wish to gain the lasting benefits of a leadership experience and help the incoming officers continue to move BHN forward.

Sincerely,

Charlotte Caperton-Kilburn, MS, RD, CSSD, LDN
 BHN Chair 2011-2012

Last Call from Charlotte: It is time for me to begin the "last call" of my tenure as Chair and to move into my next role with BHN. As the Past Chair, I will be taking nominations for the 2011-2012 BHN Awards to be given at FNCE 2012.

If you wish to nominate a BHN Member for their excellence in practice in any of the four focus fields:

- Addictions,
- Eating Disorders,
- Intellectual and Developmental Disabilities, and
- Mental Illness.

Go to <http://www.bhndpg.org/moa/awards.asp> to download the nomination forms.

Congratulations to New Officers for Year 2011 – 2012!

Chair-elect Mary Kuester, MA, RD, LD

Nominating Committee Wendy Whittenbrook, MA, RD, LD

Secretary Ellen Griffiths, RD, LDN, MPH

DPG Delegate Harriet Cloud, MS, RD

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develop programs and services that could assist our consumers as they aged. For this project in particular, those individuals experiencing symptoms of dementia and its progression. We identified a lack of communication between all disciplines; medical, speech, psychiatry, social work, occupational and physical therapy and nutrition. There was also a clear need for training of all agency staff on aging processes and dementia.

The Aging Committee pulled together clinicians to develop protocol to address the needs of individuals showing signs of dementia, the "Dementia Data Committee." Although most of our consumers in this project had DS, it was not exclusive to individuals with DS. This project was to:

1. identify symptoms and needs earlier,
2. anticipate needs so we can be proactive versus reactive,
3. be prepared with quality/effective services that make a difference,
4. identify patterns of decline,
5. provide more staff education,
6. provide care in a consistent and responsible way throughout the agency, and
7. ultimately identify what, when, and where supports benefit our consumers most.

Each discipline was responsible for developing a measurement tool using existing models, research, reports, and observations. Common measurement scales were developed in order to compare data across disciplines. Scales were similar in that the higher numbers (0 – 4) reflected worsening symptoms or a higher frequency that a particular symptom was observed. Measures were descriptive, not diagnostic. Such information was collected quarterly for each consumer in the project and the data was input into a customized database. The information can be analyzed in numerous ways:

1. scores can be analyzed on an individual basis or as a group,
2. averages within or across disciplines,
3. changes over time, and

4. noting significant "events" on a person's functional level (e.g., illness, medication change, change of residence, death in family, etc.).

Discipline assessments with rating scales addressed the following symptoms and/or functions: Psychology looked at self-care, cognitive functioning, socializing/isolation, emotional self-regulation and behavioral self-regulation. Physical Therapy included posture, muscle tone, functional mobility, perceptual/spatial skills, and abilities such as sitting, transferring, ambulation and wheelchair use. Occupational Therapy assessed dining skills, dressing, showering, toileting, fine motor coordination and changes in perceptual/spatial deficits. Speech Language Pathology noted changes in expressive language, receptive language, pragmatics, memory, attentiveness, and swallowing/dining. Nutrition assessed changes in food preferences, appetite, eating patterns, and memory around food and hunger.

The nutrition assessment rating scale used information from the National Institute on Aging, the Alzheimer's Association and other sources (1,2,3,7,8,9). The nutrition surveillance characteristics (figure 1) included:

- food choices and preferences are sporadic,
- the quantity of food consumed is sporadic,
- requires specific foods to eat, meal pattern, supplements related to the dementia,
- eats better in the morning and/or mid-day,
- doesn't remember eating last meal or snack,
- takes more than ½ hour to finish a meal, and
- misappropriates food, hoards food and/or eats non-food objects.

Given the variability in rating these questions using the percent of time observed, it was decided to note these nutrition-related functions with a "0" being "not observed or provided" and a "4" as "observed or provided."

Effects of Dementia and AD

Appetite and food desires can be affected by psychological and behav-

ioral factors such as depression, social withdrawal, agitation, wandering, paranoia, confusion, and/or irritability (usually negatively). The individual may not be aware of being hungry, may forget to eat or needs encouragement to eat. They may not be aware that their stomach is full and overeats or wants to eat all the time and may forget what they liked or didn't like to eat.

A number of these symptoms, traits and/or changes may be the result of a change in the person's life or their care and treatment. Medications and their side-effects (dry mouth, taste, hunger or anorexia, GI distress, level of alertness) can affect food intake. A food consistency change can alter how foods are perceived or recognized and affect intake. Sores in the mouth, poor-fitting dentures, gum disease or dry mouth may make eating difficult. The individual may need special utensils and dinner ware and/or other table set ups. Problems with constipation, swallowing or dysphasia, and/or congestive obstructive pulmonary disease, to name a few, can limit the desire to eat or eat adequately (3,10).

The following is an outline of the various characteristics often found in individual's with IDD in the general population experiencing dementia and AD. It offers steps to address various behaviors and eating patterns.

Eating Pattern

Breakfast (or early morning) is often the best meal eaten, followed by lunch. Persons are often more alert in the morning. Caregivers should generally serve meals and/or snacks the same time every day. If appropriate, learn what signals mean the person is hungry. If the person doesn't want to eat, take a break, involve him or her in another activity, and return to eating later. Give the person plenty of time to eat. It can take a person an hour or more to finish eating. The person may not remember when or if he or she ate. If the person continues to ask about eating a meal, consider serving one or two components of that meal, e.g., juice or fruit, cereal or bread. Use memory aids to remind the person about meal times such as a clock with large numbers, an easy-to-read appointment

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calendar, or a chalk or bulletin board for recording the daily schedule.

Food and Eating Concerns

The individual's food choices may change, not remembering their food likes and dislikes or for some other reason such as consistency change. Food taste is affected by the disease, medications and the aging process. Reduced ability to smell odors diminishes the taste of food. Aroma therapy (vanilla, rose, lemon, cinnamon) and/or the smell of food (when cooking or serving), can stimulate the appetite or help the individual be more alert. Herbs, spices (cinnamon is very good), and flavoring extracts enhance food flavors. Cheese, meat, butter and maple flavors are usually well liked as are ketchup, other condiments and gravies added to foods. The person may rely on visual cues (color) to determine sweetness and acceptability of a food. Foods with visual appeal can stimulate the appetite. Choose foods of different shapes, colors, textures and tastes, familiar flavors and see what works best. Caregivers should give the person food choices, but limit the number of choices and update a preferred food list as needed.

To help with decreased appetite, weight maintenance or gain, more calorie or nutrient dense foods may be needed. These include foods with extra healthy fats, added sugars, and protein. Preparing some of the person's favorite foods; increasing the person's physical activity; and/or planning for several small meals and snacks rather than three large meals can help. Keep track of fluid intake to ensure good hydration. Let the person participate in some phase of food making (e.g., rolling out dough, tearing apart lettuce, peeling potatoes).

Depending on chewing and swallowing abilities, the individual may need to avoid regular foods or hard or sticky foods. They may require foods cut up into bite-size pieces, chopped, ground, or pureed as well as thickened liquids to address dysphasia. Hard or crunchy foods may be disliked because of its grainy texture or it hurts the mouth. "Finger foods" can be offered

when utensils are refused or unmanageable. These include pancake roll-ups, pudding in an ice cream cone, cereal bars, vegetables and potato wedges, fortified gelatin squares, cookies, fruit with peanut butter. If the person is over eating or eating inappropriate foods; reduce access to certain foods, disguise foods that are being eaten in excess (e.g., put plain wrapper on ice cream), substitute similar foods that are healthier, provide finger food snacks regularly, and/or introduce food related activities such as kneading dough or washing vegetables.

Dining Environment and Table Setting

Provide a quiet, calm, reassuring mealtime atmosphere, limiting distractions. Soft music can be relaxing. Be patient and avoid rushing. Be sensitive to confusion and anxiety. Provide a well lit dining area with bright and contrasting colors of furnishings. Provide appropriate tables and chairs. Encourage the person to sit up straight with his or her head slightly forward. If the person's head tilts backward, move it to a forward position. Allow the person to eat with others as long as possible and best if it is in the same spot at the table.

Select brightly colored dishes that "show off" food. Avoid patterned placemats, patterned plates, printed tablecloths. Remove decorative centerpieces. Choose dishes and eating tools that promote independence. If the person has trouble using utensils, use a bowl instead of a plate, or offer utensils with large or built-up handles. Use straws or cups with lids to make drinking easier. Set bowls and plates on a non-skid surface such as a dycem, cloth or towel.

Serving Food and Assistance

Be sure the persons' and server's hands have been washed. The caregiver may need to describe the foods being served. Serving foods one at a time may improve intake. Check food temperature as the individual may not be able to tell if a food or beverage is too hot to eat or drink. Serving food warm increases its aroma and appeal. To simplify feeding tasks, serve foods ready to eat - no wrappers, buttered breads. Cut foods into-bite sized pieces before serving.

Provide direction as necessary to prompt the person to eat, chew, swallow, and drink. Be sure the food is swallowed after each bite. Be alert for signs of choking and know how to use the Heimlich maneuver. Demonstrating eating behavior or providing hand-over-hand feeding may be necessary. Tuck a napkin under the person's chin or cover his/her chest with a towel if necessary. Offer a moistened towel or napkin for washing hands after the meal (7,9,10).

Organization and Project Outcomes

Beginning in 2008, staff worked with our regional Alzheimer's Association to create classrooms in one of our day program facilities to address the needs of our consumers who are aging and experiencing the onset of dementia. Called "Spring Hill," the three classrooms had color contrasting walls and other visual and functional features and offers specialized activities. A caregiver support training program was developed and groups met on various topics. In addition, the agency established a training program to all staff that work with consumers. It included the Virtual Dementia Training™ purchased program. This was a simulated program allowing one to experience the effects of dementia and to try to complete assigned task. After the brief "exposure" there was a personal review of the experience with trained staff. Concerning nutrition, guidance, such as described in this article, has been reviewed during in service training to all group homes and day programs. The deployment of altered feeding schedules, use of nutrient dense foods and supplements, appetite-enhancing scents, and general diet flexibility have been relatively successful in curtailing nutrition degradation and undesired weight loss.

Survey Data

Data collection started in January 2010 with 23 individuals who were residents and/or day program participants with a diagnosis of dementia. Of the 23, nineteen continue to be screened quarterly. The most common characteristic seen in the 19 individuals was taking longer than a half hour to eat (fourteen),

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followed by not remembering what they last ate (ten), followed by sporadic food consumption (seven) and eating better early in the day (six). Several are on altered diets receiving nutrient dense foods and protein supplements. Three individuals present none of the characteristics being watched. Three participants had passed away from complications of disease progression. One, died in her sleep October 2011, having regressed to being tube fed three months earlier due to a poor swallow reflex. The other two had been transferred to a nursing facility for "end of life" care. They had been on a nutrient dense diet with supplements (e.g.,

fortified milk products) and a multiple feeding schedule to at least maintain their weight.

For those individuals that are in our residential program, the nutrition concerns on the screening tool are dealt with and interventions made during routine house and program visits by the dietitian. Actions taken and progress are noted in other nutrition program records. For the four individuals not in our residential program but attending the day program, nutrition dementia screen indicators were not observed at this time so no interventions have been made.

As depicted in Figure 1, data obtained from nutrition surveillance can provide the RD a new observation that may require adjustments to the nutrition care

plan as changes in the individual's level of dependence and impairment occur. In this case, the RD observes this individual's lunches monthly at program and about every two months at the residence, more frequent than the surveillance and therefore, changes to the care plan are made accordingly. Coordination with the other disciplines (OT, PT, SLP and Psych) is essential in the overall treatment and applied interventions, based on surveillance data obtained as it can affect food intake.

More detailed analysis, including linkages with changes reported from the other disciplines has not been completed as yet. This will provide a more complete picture of the individual, their disease progression and the assistance provided. This is an evolving project

Figure 1. Alzheimers / Dementia Nutrition Surveillance

Name: N C (DOB)

Rating scale:

0 – not observed or provided

4 – observed or provided

Characteristics	Date:	3/2/10	6/10/10	9/28/10	12/2/10	3/11/11	6/7/11	9/12/11	12/5/11
1. Food choices and preferences are sporadic and may change from meal to meal, day to day.		4	4	4	0	0	0	0	0
2. Quantity of food consumed is sporadic and may change from meal to meal, day to day.		0	4	4	4	4	4	4	4
3. Requires specific foods to eat, smaller and/or more frequent feedings and/or nutrition supplements, note if this diet alteration is related to a medical condition such as GERD or diabetes.		0	0	0	0	0	0	4*	4
4. Eats better in the morning and/or mid day.		0	4	4	4	4	4	4	4
5. Doesn't remember eating last meal or snack provided.		4	4	4	4	4	4	4	4
6. Takes more than ½ hour to finish a meal.		4	4	4	4	4	4	4	4
7. Misappropriates food (eg, grabs someone else's food or drinks a bottle of salad dressing), hoards food (eg, hides food under bed), and/or eats non-food objects.		0	0	0	0	0	0	0	0

Observations/Provisions by Date

1/13/10 Periods of shaking during mealtimes, cannot hold utensils, feed herself, appears very confused.

Other times, does wonderfully, eats at a decent pace, and appears to see her food and feed herself just fine.

She was finishing most of her meals and drinks.

4/21/10 Eating well. Food consistency often downgraded to ground from chopped. Weight 134 lbs.

5/13/10 Sleeping more in morning and suggested may need to adjust time lunch given.

6/21/10 Eating fair. More confused, tired. Given ¾ of her lunch at morning snack, remainder will eat later.

8/17/10 Sleeping much of time. Fed half her lunch 9:30 and 1 pm or when alert. Weight 136 lbs.

2/24/11 Eating well but slow. Weight 132 lbs. If continues to lose weight, diet will be adjusted.

3/11/11 Weight 133 lbs.

9/15/11 Eating fair. Requiring more assistance, trembling more. leaning forward a lot which hinders her eating and drinking abilities.

9/20/11 Up almost all night. tried music, total darkness, night light, comforting her but still remains awake. Sleeps well during day.

*9/21/11 Diet changed to nutrient and calorie dense foods – less volume. With fortified milk and dairy products.

10/18/11 Completing her meals and beverages.

1/12/12 Weight 133 lbs.

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with changes expected along the way to improve the coordination of care and the individual's quality of life.

About the Author: Lester Y. Rosenzweig, MS, RD, CDN is the Senior Dietitian at Schenectady ARC in Schenectady, NY. He currently serves in the BHN workgroup for the development of standards of practice and standards of professional performance in nutrition care for people with intellectual and developmental disabilities. Les can be reached at lesterr@arcschenectady.org

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CPE Credit

Continuing Professional Education credit (1CPE) is available from BHN for the article, **Addressing Dementia and Alzheimer's Disease in a Community Based Organization Serving Individuals with Developmental Disabilities with a Focus on Nutrition.**

Learning objectives: The learner will be able to 1) identify several symptoms or functions related to dementia used in nutrition, speech, physical and occupational therapy and psychotherapy discipline screening tools, 2) describe interventions to promote good nutrition for individuals with dementia, and 3) describe the preliminary findings from the nutrition dementia screening process.

Access the article, CPE quiz and certificate of completion in the *Member's Only* section at www.bhndpg.org.

New! IDD Content in Nutrition Care Manual

Nutrition Care Manual® (NCM®) is an internet-based diet and professional practice manual for Registered Dietitians, Dietetic Technicians Registered, and allied health professionals. New developmental disabilities content for NNCM® has been created by BHN DPG members: Lester Rosenzweig, MS, RD, LD; Shirley Ekvall, PhD, FAAMD, FACN, RD; and Susan Zabriskie, MS, RD, CDN.

New content includes information from the BHN IDD Resource Tool and on the topics of:

- General Guidance and Resources
- Autism Spectrum Disorders
- Cerebral Palsy
- Down Syndrome
- Fragile X
- Prader-Willi Syndrome
- Rett Syndrome
- Spina Bifida
- Inherited Metabolic Disorders
- Other Syndromes and Disorders

Academy Members receive a discounted rate to their NCM® subscription. More information can be found at <http://nutritioncaremanual.org>.

Why the Academy is Right for You: 2012 Member Benefits Update

With over 71,000 members—and more joining every day—the American Academy of Nutrition and Dietetics comprises members whose needs, interests, skills, and backgrounds span the entirety of the dietetics profession. To meet the needs of a diverse and growing membership, the Academy offers an ever-expanding array of member benefits designed to help you develop your skills, advance your career, and achieve your professional goals. As a member of the nation's largest organization of food and nutrition practitioners, you have access to a wide variety of benefits, including professional publications, networking opportunities, and professional development resources, to name just a few. With all of the benefits available to you, plus a steady stream of new and improved offerings on the way throughout each year, it can be hard to keep up with the full spectrum of career-enhancing benefits your membership allows you to enjoy.

Of course, the Academy wants you to take full advantage of all the opportunities available to you, so a listing of some of the newer and most important resources the Academy provides, accompanied by brief descriptions of their function is available on the Academy's Web site at www.eatright.org. Please feel free to share this list with your colleagues, or direct it to someone you think may qualify for membership—we've made this article open access so non-members can see what they're missing!

'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports

The National Task Group on Intellectual Disabilities and Dementia Practice provides a summary of the challenges facing the nation as we observe an increasing rate of dementia found in older people with intellectual disabilities. The Report offers recommendations for the various stakeholders in the field of IDD and anticipates that its findings and recommendations will be considered and integrated into the annual reports and plans developed by the federal Advisory Council on Alzheimer's Research, Care, and Services.

Selected key findings of the National Task Group include:

- Community services' providers are facing a 'graying' of their service population, many of whom are affected by cognitive decline and dementia, and are challenged to provide the most effective and financially viable daily supports and long-term care.
- Primary care and supports for adults with IDD affected by dementia can be primarily provided within the community and appropriate services can preclude institutionalization.
- Providers are beginning to adapt small group homes for specialized community care and supports for persons with IDD affected by dementia.
- There is a lack of background knowledge and training in late life problems of adults with IDD among primary care health providers in community practice.
- Specialized assessment and diagnostic resources are needed to help more effectively identify adults with IDD and dementia.
- Creating a national program of trainings using workshops, webinars, and other teaching methods, would advance the knowledge and skills among workers and clinicians working with adults with IDD affected by dementia.
- Creating a national information and

education program for adults with IDD and family members would improve their understanding of dementia and potentially lead to earlier identification and acquisition of timely supportive services.

- State and local developmental disabilities' authorities could more constructively forecast and budget for supporting in-community care of adults with IDD affected by dementia.

The Report concludes with a series of recommendations that comprise a **National Action Plan**

Goal A: To better understand dementia and how it affects adults with an intellectual disability and their caregivers

Goal B: To institute effective screening and assessment of adults with an intellectual disability at-risk, or showing the early effects of, dementia

Goal C: To promote health and function among adults with an intellectual disability

Goal D: To produce appropriate community and social supports and care for adults with an intellectual disability affected by dementia

Goal E: To produce a capable workforce and produce education and training materials

Citation

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In the BHN Pipeline!

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D. Milton Stokes, MPH, RD, CDN
with Jenna A. Bell, PhD, RD, LD*

Launching Your Dietetics Career is a tremendous resource for anyone considering or already enrolled in a nutrition and dietetics program. It is equally important that advisors, professors, preceptors and mentors know of this book, so that they can suggest it as a resource to students, interns or mentees. For everyone that has been a nutrition student, you know how overwhelming and confusing the path to dietetics can be. Kyle and Milton effectively describe the process of becoming a registered dietitian, ensuring that students understand the process and don't get lost along the way. There is no missing information. From accredited programs and dietetic internships to the "RD exam," this resource has you covered. The book is equally supportive of less traditional pathways into dietetics and makes the journey just as clear for career-changing students. Aside from clarifying the path to become a dietitian, Launching Your Dietetics Career offers invaluable advice to help students and new professionals stand out and be a more attractive candidate to academic programs, internships and even jobs. If that wasn't enough, the "Movers and Shakers" and "A Closer Look" sections highlight dietitians' stories of success and provide additional, specialized guidance. These sections supply great inspiration and empowerment for students to pursue and strive for their dream jobs. It also explores lesser-known positions that are held by dietitians, opening the door to endless career possibilities. It's an easy and inspiring read that is an important resource for students, interns and new graduates in the dietetics field. Available at www.eatright.org/shop.

*Reviewed by Alexandra Oppenheimer,
RD, CDN
www.ambitiousandnutritious.com*

NEW! Academy of Nutrition and Dietetics Pocket Guide to Children with Special Health Care and Nutritional Needs

Have you noticed the new BHN publication in the Academy of Nutrition and Dietetics' catalog? Over the past couple of years, BHN and PNPG have collaborated by providing experts as authors, reviewers, and editors to update the 2004 publication, *Children with Special Health Care Needs: Nutrition Handbook*. The new pocket guide is available in both print and online formats.

Children with special health care needs (CSHCN) may be defined as children with a broad range of chronic illnesses and conditions who require health and related services beyond basic, routine care. This may include children with birth defects, neurological consequences of premature birth, genetic syndromes, sequelae of infection such as meningitis, and consequences of perinatal drug exposure. Also, included in the definition of CSHCN are those "at risk" for

chronic physical, developmental, and behavior conditions, such as children with very low birth weight, metabolic disorders, extreme poverty, or environmental exposure such as second-hand smoke or exposure to lead.

The Academy of Nutrition and Dietetics Pocket Guide to Children with Special Health Care and Nutritional Needs is a valuable and must have tool for any practitioner working with this population, whether in clinical, management or community dietetics. The chapters cover the essentials to begin nutrition management for children with special health care needs. The entire guide will inspire a comprehensive interdisciplinary approach to medical management of CSHCN and is an invaluable tool to all health care professionals. Up to date scientific evidence has been translated by the authors and editors into tables and practice guidelines

that dietetic professionals will appreciate having at their fingertips. Resources and websites for additional information and case studies, some of which use the Nutrition Care Process, are included.

As with many publications through the Academy of Nutrition and Dietetics, the creation of this pocket guide would not have been accomplished if it was not for a team of exceptional professionals. I would like to acknowledge all the efforts of my co-editor, Jacque Devore, the authors, reviewers and the Academy of Nutrition and Dietetics staff members in aiding the development of this publication. Additionally, I thank BHN's Executive Committee for recognizing and supporting expert RDs and DTRs that serve CSHCN.

Andrea D. Shotton, MS, RD, LD
Co-editor for BHN

Congratulations to BHN's co-editor and BHN members who worked diligently to make this pocket guide available to all nutrition and dietetics practitioners. Find the *Academy of Nutrition and Dietetics Pocket Guide to Children with Special Health Care and Nutritional Needs* online at <http://www.eatright.org/shop/product.aspx?id=6442467529> (print only) or <http://www.eatright.org/shop/product.aspx?id=6442467916> (print + online set).

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Men and Eating Disorders

Mary E Kuester, MA, RD, LD

The National Eating Disorders Association (NEDA) reports that approximately 10% of people presenting to mental health practitioners with an eating disorder are men (1). Most health care providers believe that eating disorders in men are clinically similar to those in women (1,2). As with women, participation in sports or athletics can also place men at increased risk of developing eating disorders. Sports with a focus on weight or body size/ shape including gymnastics, running, body building, rowing, wrestling, dancing and swimming may increase the risk of disordered eating. It also appears that homosexual men are more likely to be diagnosed with an eating disorder than heterosexual men (1,2). However, there are some differences between men and women in that men feel less pressure to be thin and will often use exercise to lose weight rather than dieting (1). In contrast, men may feel more pressure to obtain a more muscular, lean physique which may drive them toward anabolic steroid abuse, excessive protein intake, and excessive or compulsive exercise.

Men, Body Image, and the Media

For many years women have felt pressure to obtain the feminine ideal that is promoted in the media. The image presented is a tall, thin, athletic female. Unfortunately, most women are unable to obtain this physique without going to extreme measures and compromising health. Likewise, the image of men and boys in the media has changed. Men are now presented as “hypermale” with a large, well developed upper body leading to a narrow waist, with washboard abdominal muscles (2). This type of physique is often obtained through the use of anabolic steroids. More and more men are becoming dissatisfied with their bodies and are beginning to use extreme measures in an attempt to achieve this unrealistic body type.

The impact of exposure to the media on boys and body image has not been well studied (3). One study of undergraduate students found that exposure to the media had a significant impact on men’s

endorsement of personal thinness and dieting (3). Boys are exposed to male body image through various media including magazines/print media, video games, toys, and movies. The average American boy spends one-third of each day exposed to media. Most of this time is unsupervised by parents (3). While women are often exposed to media messages that are more concerned with weight, men are exposed to messages about changing body shape. A content review of the 10 most popular magazines for men aged 18 to 24 found that there were more articles and advertisements focused on changing shape rather than dieting (3). These magazines included Sports Illustrated, Playboy, Newsweek, National Geographic, Rolling Stone, Penthouse, Life, Field and Stream, Jet, and Gentlemen’s Quarterly. In addition, young boys are exposed to the male ideal through their play with action figures like GI Joe and Star Wars action figures. The size and shape of these action figures has changed over time. They have become more like the male ideal presented in the media with larger and more sculpted muscles. One author speculates that if GI Joe Extreme was six feet tall, he would have larger biceps than any body builder in history (3).

Ethnicity and Eating Disorders

Ricciardelli et al (2007) reviewed studies that assessed body image for a variety of men in different ethnic groups in comparisons to Whites including: Blacks/ African Americans, Hispanic Americans, Asians, Native Americans, and Pacific Islanders (4). They found that many men struggle with body image and utilize more extreme shape control measures than Whites. However, there were some challenges including the use of non-standardized and non-validated measures. Many of the researchers used their own assessment tool. In addition, most validated body image assessment measures have been developed for use with females as it is believed that women struggle with body image more than men. These tools do not always contain information or questions that are more appropriate for men and include

questions that pertain more to body weight than to body shape.

Men, Boys and Athletics

In Western culture, male participation in athletics is often seen as a right of passage (4). In addition, the male athlete has begun to represent what is “male” in our culture. Some sports are considered to be more masculine than others and may promote positive masculine characteristics such as strength, endurance, violence and aggression (5). However, participation in athletics can often lead men into a disordered relationship with food and/ or exercise in addition to anabolic steroid abuse.

Sports that have a large focus on body shape and size may lend themselves to disordered eating. Researchers have found that the influence of the coach is important in regard to the development of eating disorders. Glazer reported that athletes who had coaches that were more focused on performance demonstrated increased anxiety around body image, increased desire to lose weight and fear of being fat (6). Some athletes that may be at higher risk are wrestlers, competitive cyclists and jockeys (5, 6). Wrestlers often engage in disordered eating and exercise to reach a weight class lower than they normally would be in. The goal is to compete at the heaviest weight in a lower weight class. Wrestlers refer to the process of losing weight quickly as “cutting weight”. In Pollack’s Real Boys’ Voices, one young man describes his pre-competition regimen like this: “Normally, to lose weight I just put on sweats and wrestle. Sometimes I put on plastics and wrestle. Plastics are made to help you sweat. ... The worst part of it is not eating. That’s hard. As of now I haven’t had a drink in twenty-four hours. I haven’t eaten in forty-eight hours. One time I lost twelve pounds in a day.” (7).

Competitive cyclists and triathletes may also engage in disordered eating to maintain a lower body weight in the hopes of being more competitive in their sport. One study found that elite cyclists scored significantly higher on an eating disorder questionnaire than their non-athletic peers (6). In addition, a

Men and Eating Disorders

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similar study among triathletes found that 11% of participants demonstrated food and weight preoccupation, 23% were restricting their caloric intake, and 100% were satisfied with their current BMI. Jockeys also are at risk for engaging in disordered eating to maintain a lower body weight. One study found that 69% of jockeys skipped meals, 67% used sauna techniques for losing weight quickly, 30% induced vomiting, and 14% used laxatives to control weight (6).

Athletes who engage in disordered eating can experience a variety of metabolic consequences including dehydration, poor performance, low bone mineral density and malnutrition. Athletes who consistently restrict their intake and maintain a lower body weight are at risk for lower bone mineral density. This is often seen in females who have anorexia nervosa (6). One study of men showed that male athletes with lower Body Mass Index (BMI), higher activity levels, and lower calcium intake were more likely to have lower Bone Mineral Density (BMD). In addition, male long distance runners with lower energy intake had lower spine BMD. It is posited that lower testosterone levels may be related to bone loss. However, for most male athletes their BMD will return to normal with weight restoration, while female athletes may not regain lost bone density (6).

Men, Boys, and Anabolic Steroid Use

Anabolic-androgenic steroids (AAS) are synthetic testosterone derivatives that are used to promote anabolic activity and decrease androgenic activity. They are used in clinical settings to treat a variety of clinical conditions including: hypogonadism, osteoporosis, and cachexia or wasting associated with burns, HIV, hepatic and renal failure (3,8,9). Negative side effects of the use of AAS are minimal when used at appropriate doses and with clinical supervision. Labre reported that an estimated 3% to 12% of male high school seniors have used anabolic steroids. He also reported that AAS were most commonly used by male students with a BMI lower than 15; students from lower socio-economic

status; Hispanic/Latino or other mixed ethnic groups; and younger students. Labre reported that athletes involved in the following sports were more likely to use steroids: gymnastics, weight training, basketball, and football. In addition, body builders and football players are also more at risk for using AAS.

One of the difficulties in determining negative side effects of steroid use is ethical considerations around research with humans. Using AAS within clinical dosages minimizes the risk of consequences. However, giving human test subjects large amounts of AAS would be unethical. Therefore, much of the information on the side effects of large doses of side effects comes from studying animals and post mortem observations (8,9). There are a variety of negative side effects including the following: changes in lipid metabolism, cardiomyopathy, sudden cardiac death, decreased libido and fertility, risk of infection, mood swings, and increased risk of substance abuse.

Changes in cardiac function are especially concerning. AAS abuse increases LDL levels and decreases HDL levels, increasing risk of heart disease. In addition, the heart muscle itself changes and it is common to see left-ventricular hypertrophy that remains after AAS abuse has stopped (8,9). Buttner and Thieme reported that a Finnish study found elite power lifters with suspected AAS use were more likely to die from myocardial infarction than the general population, with a 4.6 fold higher mortality rate (9). Another Swedish study indicated that AAS abuse is associated with early death, especially for those with additional substance abuse and/or psychiatric condition.

Another concern is the use of AAS among adolescents. Labre (2002) reported that adolescents more likely to know the benefits of AAS use are less likely to be aware of the risks, therefore are more likely to use AAS again in the future. Use of AAS also increases the potential for participating in other risky behavior such as drug and alcohol use, including other injectable drugs.

Men and Eating Disorders: Are they Different from Women?

As noted earlier, most agree that

eating disorders among men and women are essentially similar. However, researchers have found some differences (1, 2, 10), such as age of onset, different motives for weight loss and dieting, psychological distress, and differences in BMI at onset. In addition, heterosexual men may be more reluctant to seek help as eating disorders are seen as more female or homosexual problems (5).

Males have a later age of onset than females. Broman-Bosch et al reviewed male and female admissions at an eating disorder treatment facility and found that males presented an average of five years later than females (2). This may be related to changes in body composition during puberty. Girls may begin to engage in disordered eating at an earlier age because the changes in body composition during puberty move them further away from the feminine ideal. In contrast, puberty brings males closer to the masculine ideal (10). In addition, differences in socialization between boys and girls may impact body dissatisfaction with girls becoming more dissatisfied with their bodies from the waist down, whereas boys are more dissatisfied from the waist up.

Men often diet as a means to an end, whereas females engage in dieting as a social practice or norm. Men or boys may have different motives for dieting or losing weight than women including:

- avoiding repetition of childhood teasing around weight/ body size,
- improving athletic performance,
- avoiding weight related medical problems that were experienced by their father,
- or to improve gay relationships (10).

In addition, men are more likely to use exercise as their primary strategy for weight loss whereas women will use caloric restriction (5). Men may also engage in binge eating or use/ abuse of nutritional supplements to gain weight (3,4). The nutritional supplement industry has experienced exponential growth in the last decade and these unregulated substances are readily available for use and include oral steroids, creatine, and protein powders (3).

A number of researchers have found that males with eating disorders are also more likely to have a co-morbid mental health problem, including anxiety, depressive disorders, schizophrenic/

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psychotic episodes and substance abuse (2,5). In addition, Bramon-Bosch et al found that males were more likely to engage in suicidal behavior than females (50% versus 23%) (2). This may be related to differences in diagnosis for men and women in general, in that eating disorders in men may only be diagnosed when there is another morbidity.

Andersen and Holman reported that males were at a higher BMI when they began to diet than females (10). They found that the average maximum BMI for males was within the range of obesity, whereas the BMI for females was within the normal range. This difference was eliminated at presentation for treatment.

Most clinicians recognize that homosexual men are more likely to present for treatment than heterosexual men (1,2,5). The exact reason why is unclear at this time and further research would likely be helpful. However, some believe that this may be related to the feminization of eating disorders and dieting, and the idea that heterosexual men are afraid to have a "women's problem" or be labeled as "gay" (5).

Men and the Treatment of Eating Disorders

Most research on the treatment of eating disorders has included small numbers of men in the sample size, making it difficult to determine if there are different modes of treatment that are more effective with men than women (2,6). However, most agree that treatments with women can also be used with men. Andersen and Homan reported that the more severe the illness at presentation, fewer gender differences occur (10). However, as men begin to regain their health, the differences in gender may become more important and men may benefit from programming that addresses their gender related concerns. Below are some treatment modalities to consider:

- Weight restoration for those who are below a healthy weight range
- Restoration of normal eating habits including eating a variety of foods regularly throughout the day
- Limiting or discontinuing participa-

tion in sports and competition until weight is restored

- Addressing concerns about abdominal weight gain which may trigger relapse
- Assessing biochemical markers such as testosterone levels and Bone Mineral Density
- Evaluating the use of AAS and nutritional supplements
- Assessing body image disturbances including body dysmorphism or drive to obtain ideal male physique
- Assessing cultural norms that may impact body image
- Assessing for other mental health conditions such as depression, anxiety, and substance abuse
- Education on the role of different nutrients in the body and their importance in their diet
- Addressing any concerns regarding body image and sexual orientation
- Screening student athletes who participate in high risk sports such as wrestling, gymnastics and football for disordered eating or use of AAS

The RD plays an essential role in the treatment and prevention of eating disorders in both men and women. It is important for dietitians to be aware of potential differences between the needs of male and female clients and make adjustments as needed.

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Partial Starvation Effects on Men: A Landmark Research

The 1944 Minnesota Starvation Study conducted by Dr. Ancel Keys provides a glimpse of pro-longed semi-starvation and symptoms/behavior seen in anorexia nervosa. Volunteer conscientious objectors (34 male human subjects) during WWII were provided a famine type of diet for 6 months to study the effects of starvation. The starvation period was preceded by a 3 month control period and a 3 month rehabilitation phase. During the experiment, the men demonstrated behaviors such as reading recipes, not wanting foods to touch on the plate and obsessive compulsive-type issues around food that were never seen at normal weight. The average weight loss was 24% and measurements taken demonstrated a decrease in every respect measured, including stature. Participants exhibited:

- preoccupation with food, both during starvation period and rehabilitation,
- drastically reduced sexual interest,
- social withdrawal and isolation,
- declined concentration, comprehension and judgment capabilities with no diminished capacity,
- marked declines in physiological processes indicative of decreased BMR, and
- some symptoms and behaviors seen in anorexia nervosa.

More information on this landmark study can be accessed in The American Society for Nutritional Sciences. *J. Nutr.* June 2005; 135:1347-1352 at <http://jn.nutrition.org/content/135/6/1347.full>,



Marley Peale Braun, MS

Student Spotlight: Psychological Symptoms of Celiac Disease

By Marley Peale Braun, MS, CN

Attending college means pursuing opportunity, but students with food allergies may feel preoccupied with monitoring their diet in this new environment.

Students, especially those living on campus, usually depend on the university or college for providing meals. Although a savvy dining services staff can be an asset to those with food allergies, students may feel apprehension in trusting an unfamiliar system. College students who choose to take responsibility for their own meals may be faced with limited space, equipment, and resources. Managing a food allergy, like celiac disease, can be difficult. It is important for college students to seek help. In the case of celiac disease, psychological difficulties first experienced as a symptom of the condition can also occur during disease management.

Celiac disease is estimated to occur in one out of every 133 Americans, and is characterized by an autoimmune response to gluten, proteins found in wheat, rye, and barley (1). Resulting damage to the small intestine prevents nutrients from being absorbed, which can lead to serious health consequences (2). Symptoms are not always present, but physical indications like abdominal cramping, intestinal gas, migraine headaches, and bone or joint pain can occur, as well as psychological manifestations, such as brain fog, anxiety, and depression (2). Nutritional malabsorption may be responsible for those psychological symptoms. Deficiencies of certain vitamins, minerals, and amino acids have been found to effect mental functioning (3).

Adhering to a gluten-free diet is the only treatment for celiac disease (2). Presumably compliance would control symptoms, but for some individuals psychological problems still occur (4). Survey data compared women both with and without celiac disease and found that those with celiac disease had more depression and disordered eating. This was true even when celiac sufferers followed a gluten-free diet (4).

Individuals with celiac disease may display symptoms of disordered eating or obsessive-compulsive disorder due to constantly monitoring dietary intake and fears of cross contamination. Disturbed mental functioning seems to be associated with celiac disease – both before treatment, possibly arising from lack of nutrients related to malabsorption – and after treatment, perhaps associated with diminished quality of life related to a restricted diet. More investigation is needed to fully understand the connection between celiac disease and mental health.

In the meantime, students with food allergies can manage dietary needs and prepare for possible psychological and behavioral challenges with these suggestions:

Form a social club

A club can serve as a support group and a way to meet other students with similar challenges. You don't have to have a food allergy to attend. Students in the field of nutrition can help introduce allergy-free foods to the group. Make sure to recruit off-campus members to host allergy-free potlucks.

Investigate sources

Visit the campus dining halls and cafeterias. Talk to the staff. Don't be afraid to ask questions and make suggestions.

Utilize student services

Is there a Registered Dietitian on staff? If not, advocate for this important position. A Registered Dietitian will provide expert advice related to appropriate food choices. If you are experiencing depression or disordered eating, they can also provide support and make a referral to a mental health counselor when necessary. Don't be afraid to ask for help – you shouldn't have to manage your food allergy alone!

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Time for BHN Awards!

Time to spotlight those among us who have shown "Excellence in Practice" and to celebrate one BHN member as recipient of our "Distinguished Member Award." Go to www.bhndpg.org/about/awards.asp for BHN awards criteria, guidelines, and forms to nominate members you know to be deserving of either of these two awards. For questions contact Charlotte Caperton-Kilburn at nflperformance@yahoo.com.

Application Deadline is June 1, 2012.

In Search of Evidence . . .

1. <http://pediatrics.aappublications.org/content/early/2011/07/21/peds.2011-1605>

Bull, MJ, and Committee on Genetics. Clinical Report--Health Supervision for Children with Down Syndrome. Pediatrics. Web site, July 25, 2011.

Children with Down syndrome have medical conditions and cognitive impairment related to extra genetic material on chromosome 21. Three-quarters of these unbalanced translocations are de novo, and the remainder result from familial translocations. Of special interest to Dietitians, this report includes recommendations to address feeding issues of infants such as problems related to hypotonia, (slow feeding, choking with feeds, recurrent pneumonia, unexplained failure to thrive), constipation, and gastroesophageal reflux. Noting that previously used Down syndrome specific growth charts no longer reflect the current population styles and body proportion, assessment of growth and weight should utilize standard growth charts and should include use of weight for height and BMI. Regular review for symptoms potentially related to celiac disease, (diarrhea or protracted constipation, slow growth, unexplained failure to thrive, anemia, abdominal pain or bloating, or refractory developmental or behavioral problems) is recommended. There is no evidence showing routine screening of asymptomatic individuals as being beneficial. Families are encouraged to establish optimal dietary and physical exercise patterns that will prevent obesity. (Type of evidence: Expert Opinion)

2. <http://www.ncbi.nlm.nih.gov/pubmed/21219517>

Tsai AC, Chou YT, Chang TL. Usefulness of the Mini Nutritional Assessment (MNA) in predicting the nutritional status of people with mental disorders in Taiwan. J Clin Nurs. 2011 Feb;20(3-4):341-50. doi: 10.1111/j.1365-2702.2010.03467.x.

Nutritional status of people with schizophrenia, major depression, and bipolar disorder in Taiwan was evaluated with a content-equivalent version of the Mini Nutritional Assessment. A structured questionnaire elicited subjects' personal data, disease history and answers to questions in the Mini Nutritional Assessment. Serum and anthropometrical parameters were measured. The Mini Nutritional Assessment predictions of malnutrition agreed well with other nutritional indicators such as BMI, waist circumference and appetite status. According to the Mini Nutritional Assessment-Taiwan version-1, people with major depression were more likely to be at risk of under-nutrition, whereas people with schizophrenia or bipolar disorder were more likely to be at risk of over-nutrition. (Type of evidence: Instrument validation for psychiatric population)

3. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3006050/?tool=pmcentrez>

Standards of Medical Care in Diabetes—2011. Diabetes Care. 2011 January; 4(Supplement 1):S11-S61
Of special interest to RD's who perform physical

Acanthosis nigricans is a skin disorder in which there is darker, thick, velvety skin in body folds. Very visible markings and creases appears in the armpits, groin and neck folds, and over the joints of the fingers and toes. It can be related to medical problems or genetically inherited. It is often found in people with obesity-related diabetes. Some drugs, particularly human growth hormone or oral contraceptives can also cause acanthosis nigricans. People with cancers of the gastrointestinal or genitourinary tracts can also develop severe cases. <http://www.nlm.nih.gov/medlineplus/ency>

examinations: Observation of acanthosis nigricans is one criteria for testing for diabetes in otherwise asymptomatic adults. Testing/screening should begin at age 45 years and repeated at 3-year intervals depending on other risk factors. In section V. B. the standards define the teams for diabetes care to include, but are not limited to, physicians, nurse practitioners, physician's assistants, nurses, dietitians, pharmacists, and mental health professionals with expertise and a special interest in diabetes. This reflects the increasing interest in the correlation found between diabetes, depression and other mental illness. A calculator for converting A1C results into estimated average glucose (eAG), in either mg/dl or mmol/l, is available at <http://professional.diabetes.org/eAG>. (Type of Evidence: Expert Opinion)

4. <http://alcalc.oxfordjournals.org/content/46/1/77.full.pdf+html>

Barbadoro, Pamela, Eliza Ponzio, Maria Elisabetta Pertosa et al. The Effects of Educational Intervention on Nutritional Behaviour in Alcohol-Dependent Patients. Alcohol and Alcoholism 2011; 46(1):77-79. doi: 10.1093/alcalc/agq075

Results of a nutrition education included in a multi-discipline treatment program indicated that alcohol-dependent individuals are receptive to messages regarding nutritional health. Before the intervention 19% consumed 3 meals/day. In a telephone interview 6 months later 70% reported consuming 3 meals/day. Researchers concluded well-designed on eating behavior may prevent malnutrition and favor abstinence after treatment. (Type of Evidence: Observational)

5. http://www.flyingpublisher.com/pdf/FPG_008_ComplementaryandAlternativeMedicineTreatmentsinPsychiatry_2012.pdf

Stradford D, Garry V, Christine B, Hyla C. The Flying Publisher Guide to Complementary and Alternative Medicine Treatments in Psychiatry. Flying Publisher & Kamps. 2012 Edition.

This 110-page book covers the basic aspects of many nutrients, allergies, celiac disease, toxins, and their effect on mental status as well as material on lifestyle change, mindfulness, breathing techniques, and yoga. It is free to download from the above web site. The site provides access to numerous other resources. You and your favorite psychiatrist may like to have this reference. (Type of Evidence: Review)

Complied by Ruth Leyse-Wallace, PhD, RD at rthlys@cox.net.

Nutrition Informatics: The Intersection of Information, Nutrition, and Technology

Health care reform and patient care delivery are on the fast track in the United States because of recent legislation and several landmark documents. As a result, health care professionals, including registered dietitians (RDs) and diet technicians registered (DTRs), as well as vendors, government organizations, and many associations, such as Academy of Nutrition and Dietetics (formerly the American Dietetic Association [ADA]), are stepping on the gas to keep up with all the changes that are taking place.

Nutrition education resources, the ability to search for information, and technology skills have seen significant changes since the time when computer systems were introduced many decades ago. As other professions began to recognize the importance of “informatics” as it applied to their area of practice, so did ours. In 2007, ADA formed the Nutrition Informatics Work Group, which defined “nutrition informatics.”

The formal definition, based on an established definition for biomedical informatics, is:

“The effective retrieval, organization, storage, and optimum use of information, data, and knowledge for food and nutrition related problem solving and decision making.” “Nutrition informatics is the intersection of information, nutrition, and technology.”

In 2010, in recognition of the importance of ongoing work in this area, the Nutrition Informatics Work Group became the Nutrition Informatics Committee (NIC). The NIC translated this formal definition into a simple line, 140 characters in length:

Even before the formation of the Nutrition Informatics Work Group and NIC, ADA was taking steps to position the dietetics profession in the informatics arena. Beginning in 2002, the International Dietetics and Nutrition Terminology standardized language for nutrition professionals, the Nutrition Care Process and Model, and the Evidence Analysis Library were developed, all reflecting the use and value of nutrition informatics in dietetics practice.

Present Implications

This is an exciting time as health care professionals look at the ways informatics will impact their profession and individual areas of practice. In fact, many

dietitians – whether educators, researchers, businesspersons, or consultants—already use informatics without even realizing it.

Here are some examples:

- Clinical dietitians use electronic health records (EHRs) to assess, diagnose, and implement appropriate care plans and track outcomes
- Management dietitians use informatics to manage personnel, budgets, food procurement, production, inventory, and delivery of meals
- Community dietitians use databases to provide up-to-the-minute global public health surveillance and to monitor disease outbreaks around the world
- Businesses and consultants take advantage of social media to brand themselves, their services, and their products, using blogs, portals, and tweets on a daily basis
- Researchers use informatics for accessing databases, developing protocols, capturing data, and submitting research
- Educators have access to online applications and networking, with simulation and newer technologies replacing PowerPoints and lectures in the classroom

Health care is moving toward “data following the patient” and the expectation of “interoperability” of data between and within EHRs. However, as health care professionals witness the exciting changes that are taking place, they also must recognize the importance of protecting individuals’ privacy and security. Like all health care providers, it is necessary to abide by the Health Insurance Portability and Accountability Act (HIPAA) regulations, sharing a person’s information only through secure, encrypted, and/or password-protected means of communication.

Future Implications

Health care professionals are not the only ones who will use information and technology to diagnose and treat illness. Portable electronic devices and other forms of mobile health (mHealth) help patients play an active role in their care. Sensors are available to allow individuals to report important information about their blood pressure or blood

glucose directly to their health care provider. They even can enter information about the lunch they just consumed and send it to their dietitian via a picture or a portal.

Resources

All of these changes will require collaboration at all levels of health care and education. Just keeping up with the vocabulary alone can seem overwhelming. Legislation and initiatives like the Health Information Technology for Economic and Clinical Health (HITECH) Act, Technology Informatics Guiding Educational Reform (TIGER), and Meaningful Use may not have seemed relevant to dietetics practice at first. RDs and DTRs are quickly learning how important each of these is to our profession and how critical it is to keep up with the latest developments. More and more Academy members are regularly reading *Eat Right Weekly* so they don’t miss important and timely updates.

To help keep you on the fast track, the Academy has many resources available. Here are just a few:

- Nutrition Informatics Blog
- Nutrition Informatics On-Line Community
- Academy/AMIA 10x10 introductory biomedical informatics course
- EHR Toolkits

Summary

The United States is moving toward an electronic health care system at an extremely rapid pace. Because of their education and experience in many areas of practice, RDs and DTRs are well positioned to participate in this exciting transformation. The Academy also is working at many levels to help RDs and DTRs embrace the idea of nutrition informatics. The intersection of nutrition, information, and technology will provide the opportunity for RDs and DTRs to help reduce costs, reduce errors, and provide better care, regardless of area of practice.

Academy members are welcome to join the on-line Nutrition Informatics Community, where sharing of information and ideas is welcomed and encouraged.

BHN Members Speak Out at NAMI

By Milton Stokes, MPH, RD, CDN

The National Alliance on Mental Illness (NAMI) is a grassroots mental health organization that supports, educates and advocates for those living with a serious mental illness and their families. The organization got its start in 1979 when family members who had loved ones living with schizophrenia banded together to support and advocate for each other. From this beginning, NAMI has grown and now has affiliates in all 50 states, the District of Columbia, Puerto Rico, the Virgin Islands and Canada. Most members come to NAMI when in crisis looking for support and practical help on how to access the mental health system.

A major initiative of NAMI and other mental health organizations is to improve the overall health of those living with a mental illness. The help of dietitians is critical. The life expectancy for those with a serious mental illness is as much as 25 years less than for the general population. There are a lot of factors that contribute to this statistic, but one reason has been that not much attention has been paid to the whole body of those with mental illness. The only concern has been with the one organ – the brain. The theme of the 2012 NAMI National Conference (June 28-30, 2012 in Seattle) is “Think, Learn and Live: Wellness, Resiliency and Recovery”. BHN member and award recipient, Ruth Leyse-Wallace, PhD, RD is

“There is a pressing need for dietitians to be involved in helping those living with a mental illness”

a symposia speaker and later in the day Patti Jo Severnson, MS, RD, I and two persons living with a mental illness will conduct a practical workshop on ways to eat more healthfully. There is a pressing need for dietitians to be involved in helping those living with a mental illness to lead long productive lives.

NAMI has three levels of organization: local (called affiliate), state and national. Each has its part in fulfilling the mission of support, education and advocacy to help individuals and families affected by mental illness. For example, the affiliate runs support groups as well as 12 week Family-to-Family and 9 week Peer-to-Peer education courses. The content and

structure of these programs is developed by the national team, the state provides the training, and the affiliate provides the volunteers to teach the classes. All NAMI programs are free of charge. The Family-to-Family course is one of NAMI’s most popular signature courses. It is an evidence-based program that has been shown to “significantly” improve coping and problem-solving abilities of family members of individuals living with mental illness, according to a landmark study published in *Psychiatric Services* (1). As a person who has taken the course and now as a volunteer teacher, I can attest to the enormous impact the 12 week class has on families’ lives.

The community of hope is one of the most salient features of NAMI for many members. Through support groups and education programs families gain skills and knowledge. As a past state president, and a current affiliate president and NAMI national board member, I continue to witness the difference NAMI makes in people’s lives.

Advocacy for those living with a mental illness is a shared activity by all levels of the organization. Although mental illness affects millions of Americans, it is difficult to get the general public interested. The advocacy efforts of NAMI are critical to making sure services and research continue to be provided. It would be wonderful if

everyone who was touched by mental illness joined in this effort. However, the stigma around

mental illness is very powerful and prevents many from seeking help.

For more information on NAMI, go to the website www.nami.org. If you are working with clients living with a mental illness, please consider joining. Living with a mental illness is not easy and is made all the more difficult due to stigma. The support of more people is necessary to change popular perceptions. This organization respects the diversity of all who are living with a mental illness and their families and strives to be inclusive. No one should have to face mental illness alone.

1. Dixon L, Lucksted A, et al. Outcomes of a Randomized Study of a Peer-Taught Family-to-Family Program for Mental Illness. *Psychiatric Services*, June 2011; 62 (6) 591-59.7

Public Policy Update Spring 2012

**Cinde Rutkowski, MA, RD,
BHN Public Policy Liaison**

The 2012 Academy of Nutrition and Dietetics' Public Policy Workshop (PPW) is scheduled for April 15-27 at the Crystal Gateway Marriott Hotel in Arlington, Virginia. PPW is the premier policy and advocacy training for Registered Dietitians (RD) and Dietetic Technicians Registered (DTR) sponsored by the Academy.

I am honored and excited to be your BHN representative and look forward to learning more about the following issues that we as Food and Nutrition Professionals are currently facing in regards to Nutrition Policy at both the federal and state levels.

- CMS Update
- The Academy Political Action Committee (ANDPAC) update
- Key federal and state issues including:
 - Farm Bill Reauthorization
 - Older Americans Act
 - Drug Shortages and Effects on TPN and Vitamin/Mineral Solutions
 - MNT and Prediabetes
 - State Insurance Exchanges
 - Licensure
- The Marketing of Food to Kids
- Let’s Move...RDs Leading the Way to a Healthier Generation initiative and its impact on both members and consumers

If you have a particular legislative issue that you would like me to obtain more information on, please email me at rutkowskic@michigan.gov.

BHN PUBLICATIONS

The Adult with Intellectual and Developmental Disabilities

This resource tool is designed to provide an overview of nutrition in individuals with intellectual and developmental disabilities. The resource guide is contained on one CD-ROM as a 209 page PDF file.

BHN Member Price: \$28.00



Psychiatric Nutrition Therapy

This resource guide is intended for anyone working in the 4 practice areas within Behavioral Health Nutrition: mental illness, eating disorders, addictions, and those with intellectual and developmental disabilities who also require psychiatric care. The resource guide is contained on one CD-ROM as a 170-page PDF file.

BHN Member Price: \$28.00

Nutrition & Addictions

This is a 244-page manual of information about addiction and drugs of abuse, including legal, illegal and pharmaceutical drugs, alcohol, nicotine, caffeine, and more. Patient educational handouts on nutrition and recovery topics are also included.

BHN Member Price: \$24.95



To order, visit <http://www.bhndpg.org/publications/index.asp>

Please Help Us Adapt Obesity Prevention Strategies for Youth with Disabilities

In 2009, the CDC initiated the Common Community Measures for Obesity Prevention Project to identify a set of strategies that communities and local governments can use for obesity prevention and reduction. These strategies were developed from an evidence-base of research that typically excludes participation by people with disabilities.

The obesity-prevention strategy adaptation portal, www.24acorns.org, was created so that persons with disabilities, teachers, clinicians, researchers, policy makers, and more could have a place to contribute their input on how to best adapt the CDC's 24 obesity-prevention strategies to be inclusive for youth and young adults with disabilities. Long story short – **we need your help!**

The featured strategy in March is: communities should increase the availability and affordability of healthier food and beverage choices in public venues. Offering affordable, healthy choices might increase the consumption of healthy foods. We want to know what suggestions you may have in order to help communities offer healthier food and drink options in schools, child-care centers, community recreation buildings, county buildings, and other public venues.

To contribute your suggestions, please visit www.24acorns.org and click on the "Featured Strategy" button on the bottom of the page.

The "Adaptations to Community-based Obesity Reducing National Strategies" (ACORNS) website is part of a grant funded by the National Institute on Disability and Rehabilitation Research (NIDRR). The website is a development of the Disability and Rehabilitation Research Project (DRRP), which is aimed at addressing the gap in the availability of obesity reduction programs and obesity prevention strategies for youth and young adults with disabilities.

The ACORNS website and the DRRP study are imperative at a time when obesity rates in adolescents aged 12 to 19 years have more than tripled over the past three decades, and have doubled for children ages 6 to 11 years. The obesity epidemic is even worse among youth and young adults with disabilities. Reversing this trend requires a comprehensive approach that uses policy and environmental change to transform communities into places that promote healthy lifestyle choices for all. With your help, we can begin utilizing a translational research approach to provide equal opportunities to everyone for a healthy lifestyle.

Please help to spread the word! Direct anyone you know who may have experience or expertise on how to adapt programs for persons with disabilities to www.24acorns.org. There, you can submit your suggestions for physical, cognitive, or cultural adaptations to any of our 24 featured strategies. For more information about the project, contact Jessica Madrigal via email at Jmadri1@uic.edu or via phone at 312-355-5295.

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