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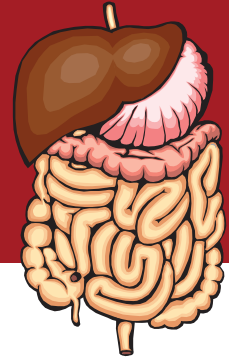
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CELIAC DISEASE: A GENETIC DISORDER THAT AFFECTS NUTRITION



Celiac Disease (CD) is a genetic, inheritable disease that may be under diagnosed in the DD population. People with CD have an autoimmune response in their bodies to eating certain types of protein, called gluten. An autoimmune response is when the body attacks itself and causes damage to the small intestine (called villous atrophy). When this occurs, the small intestine cannot absorb the nutrients in food leading to malnutrition of the individual and an array of other problems. This is a problem of all age groups with young and old, alike, being afflicted with it. It is NOT to be confused with a food allergy and does not cause the typical histamine-release seen in allergic reactions.

“Gluten” is a generic term for a certain type of protein found in grains such as wheat, rye, barley, oats, corn, and rice. In general, people with CD need to limit or eliminate wheat, rye, barley, and in lesser amounts, oats. Limiting these grains and the foods that contain them, will keep the disease from progressing. It is not known why the disease ‘shows up’ at a given time in a person’s life, but 3 factors must exist for the disease to take off. There must be a genetic predisposition for the disease to start with. Secondly, the person has most likely been eating a diet high in wheat, barley, rye, and oats. Then finally, a trigger of some kind has occurred that causes the disease to become active in a person’s body. This trigger could be any stressor in this person’s

life, emotional, physical, dietary, and may follow a bout of illness in which the person’s immune system did not respond quickly enough...or they got sicker than would be expected before recovering.

Symptoms of CD can be difficult to identify sometimes. CD is known as one of the “great mimics” in the GI world, with some patients having a wide variety of symptoms and others having no symptoms at all. It can easily be diagnosed as something else (see the symptoms list below.) It is estimated that in 33% of people with CD, it is a silent disease. They do not have overt symptoms but the CD is causing malabsorption of nutrients and other problems in their bodies that physicians and nurses may not be able to pin down the cause of.

So what are some of the symptoms?

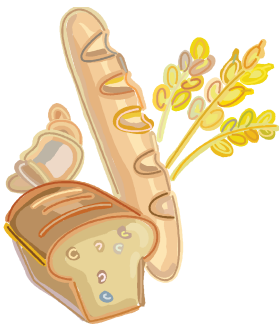
Back pain, abdominal cramps, bloating, constipation, dehydration, diarrhea, passing gas, mouth sores, cracks around the lips, dry skin, bowel movement changes, night blindness, muscle cramps in hands or feet, fatigue, weight loss, weakness, edema, electrolyte abnormalities, tooth enamel defects, tongue looks abnormal (smooth or blotchy), reduced foot padding, anemia.

Do any of your consumers have any of these symptoms? More than one? Several? Additional emotional

symptoms such as depression, irritability, and mood changes are also common. With the individuals who have communication disorders, this may be the only sign you see of Celiac Disease!

If you suspect that someone you provide services for, yourself, or a family member has CD, you need to ask your physician for a **Celiac Blood Panel to aid in diagnosis**. This includes blood tests (EMA, AGA, AGG, tTGA) that measure levels of certain antibodies in your system. There are also 2 tests to measure your tolerance of digesting and absorbing certain foods (lactose tolerance test & the D-Xylose test). If the disease has progressed to later stages and malabsorption is evident, a biopsy of the small intestine (jejunum) would be necessary. The final step in diagnosing CD is to put the person on a gluten-free diet for 6 months. If they greatly improve, this is diagnostic for Celiac Disease.

Celiac Disease is a chronic disease and there is no cure at this time, however treatment with a strict gluten-free lifestyle can greatly improve health and well being indefinitely. Information for this article and more info can be found at: <http://www.csaceliacs.org>



MEDICATION TITRATION: WHEN THE PHYSICIAN INCREASES OR DECREASES THE DOSE OVER TIME

Medication administration actually begins with the prescription written by the physician or their designee. Although following a prescription may seem to be a straightforward process, often it is not...because every physician or physician's designee does not write the script the same way as another physician may. It is important that every prescription is clear and concise AND contains all of the components required to fill the script and to eventually administer the medication safely.

Additionally, there are some prescriptions that can be more difficult to follow due to multiple instructions within one script or other reasons. Titration of doses is one of these situations that confuses direct care staff often...it even confuses nurses, and if actual written scripts are any evidence...it confuses physicians as well.

Titration of a medication means that doses are either going up or going down over time. There may be an assessment involved by the nurse as in the case of titrating pain medication for someone who has cancer in hospice services. The dose is increased or decreased based on a pain assessment done just prior to administering the medication. This is common with hospice patients.

Titration may also be utilized to decrease a medication that someone needs to be taken off of due to side effects or no therapeutic effect seen while on the med. There are medications that should always be titrated down when discontinued and should never be suddenly removed. There are medications that, due to their potential side effects, should be slowly increased when started to minimize the actions of these side effects. It is even possible to have one medication being titrated DOWN while another medication that it is being replaced with, to be titrated UP! Medications that require titration to safely increase or decrease doses will have these recommendations listed in your PDR or Nursing Drug Reference. You can also find recommendations for dosing frequency online for every medication at FDA MedWatch (Google it).

Determining the best dose for your consumer or helping them determine the best dose can be tricky. It is generally accepted that the physician should start with a lower dose than the expected dose you may end up with. There is a dose (or dosage range)

that will be identified for each medication and some demographic groups (children, adults, people with renal impairment, etc.) that was determined through much research to be the optimal dose or range. The recommended method for prescribing many psychiatric, seizure, heart, pain, and other medications is to *start low...and go slow*. This means start at a dose that is 25—50% below the listed therapeutic dose and increase it according to assessments related to that medication's and/or consumer's symptomology. If you have a consumer taking Zyprexa for psychosis related to Bipolar Disorder, you are going to initiate documentation of the behaviors exhibited by this consumer related to the psychosis. Document frequency, time of day, precipitating factors, as much information as makes sense...before and after dose increases until you reach a therapeutic level for that person. **THE GOAL IS TO ACHIEVE THE MOST BENEFIT TO THE CONSUMER WITH THE LEAST AMOUNT OF MEDICATION.** Some people do very well on low doses of a medication. The next person may take 10 times that amount to do as well. If the physician titrates the medication and the documentation based on observation and assessment backs it up, you are on the right track. Do not assume that everyone will have the same therapeutic effect at the same dose...or on the same medication. There is no medication or dose of medication that will work for everyone.

Research has shown that the classic dose response curve reveals that about 25% of patients will have the desired effect of a drug at low doses. And at the top end of the curve are people who will not have any additional benefit or response by increasing the dose more. There is a significant amount of people (studies reveal 10-30%) who are non-responders. Increasing doses for these people would only add adverse effects and cost.

This is the reason why titration of new medications is important. To get to the most effective dose with the least amount of medication.

Transcribing titrating doses is tricky. Ask your nurse or call the pharmacist for assistance if you need to. **DON'T GUESS!**



MEDICATION DOCUMENTATION: MAKING SENSE OF TITRATED DOSES

		1	2	3	4	5	6	7	8	9	10	
Depakote 125 mg by mouth three times a day For Seizures Order date: 10-01-08	7am	qS	qS	DC	11-03-08 (see dose increase below) GS							
	12 n	qS	qS	qS	qS	DC	11-05-08 (see dose increase below) GS					
	7 pm	qS	qS	qS	qS	qS	qS	DC	11-07-08 (see increase below) GS			
(Increase Depakote by 125 mg every other day to a total of 750 mg per day) BEGIN Depakote 250 mg by mouth at 7 am. For Seizures Order date: 11-03-08	7 am		→	qS	qS	qS	qS	qS	qS	qS	qS	
(Increase Depakote by 125 mg every other day to a total of 750 mg per day) BEGIN Depakote 250 mg by mouth at 12 n. For Seizures Order date: 11-03-08	12 n				→	qS	qS	qS	qS	qS	qS	
(Increase Depakote by 125 mg every other day to a total of 750 mg per day) BEGIN Depakote 250 mg by mouth at 7 pm. For Seizures Order date: 11-03-08	7 pm							→	qS	qS	qS	qS
									↑			
									↑			
AFTER THE TITRATION TO THE NEW DOSE HAS OCCURRED, THE ENTIRE ORDER CAN BE REWRITTEN AS:												
Depakote 250 mg by mouth three times a day For Seizures	7 am 12 n 7 pm											

Depakote 750 mg total per day after titration of doses

PHYSICIAN'S ORDER (a physician may write any of these or have other options):

Increase Depakote to 750 mg total/day by increasing 125 mg every other day. Seizures.

OR

Titrate Depakote to 250 mg po TID in 1 week. Dx: Seizure Disorder

OR

Increase Depakote as follows: 11-03-08 Give 250 mg @ 7 am, 11-5-08 Give 250 mg @ 12 noon,
11-07-08 Give 250 mg @ 7 pm, Continue 750mg po per day for seizure control.

THE POST SCRIPT

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All articles to be considered for submission to this newsletter should go to Georgia Swank at the above email address. We welcome your comments and ideas!

TRANSCRIPTION TIPS: TITRATION

- Communicate med changes in your communication logs, reports, and in person when shifts change
- Divide your order so that each different dosage is on a separate line on the MAR
- Cross out boxes on the MAR that correlate to NO med being given at that time or on that day
- DC (discontinue) a dose when it is changed by either increasing or decreasing
 - *Write DC, the date, your initials
 - *It is preferred to write "see order change below" or some "connector" to alert future med passers to the changes
 - * Yellow out the line that is DC'd to decrease potential errors or overdose
- Go back and RECHECK your dates, times, and dosages.
- Call the nurse or your pharmacist if you have problems transcribing any order or fax it to the pharmacy to be double checked if you are not sure
- DO NOT GIVE ANY MEDICATION if you question the order or how it is written!

CONSUMER & FAMILY EDUCATION

Providing education to your consumers and their families can be a challenge. This is the job of all healthcare providers from Executive Directors to Nurses to Program Directors to Quality Managers to Direct Support Professionals. Each person plays a role in the growth and development of the individuals we support and their families. There are loads of resources on the internet that can be accessed and downloaded to be used for training in every area you can think of. In addition, there are many formats such as podcasts, videos, written fact sheets with pictures, webinars, websites and even online help persons at sites to answer their questions about healthcare issues in real time! E-learning (electronic learning) will guide even the most basic learner through the information to help them succeed. People can learn at their own pace, sometimes even get DVDs or CDs sent to them for learning at home. Using computers in group homes and supported living to enhance the learning opportunities of our consumers, families and others is a great tool for bringing the education to the person...no matter where they are. This also can give them access to healthcare information about their medications, their medical conditions, and provide them with many independent learning experiences for things like dieting and exercising on their own.

Some barriers may exist for some individuals in using e-technology;

- Lack of computer availability

- Lack of training on a computer, limited assistance from staff
- Disability that affects one's ability for fine motor coordination or sight
- Lack of finances to purchase a computer
- Internet access issues

There are screen magnifiers, software that reads the screen to you, hearing amplifying systems, Braille keyboards, head or eye-controlled inputs, color coding, spell checking, speech recognition and other technology miracles. Computers are available at most libraries free of charge to those with a current library card. The passionate organization, parent, or consumer looking for a way to create e-learning situations, can do it.

Some sites that provide great learning options are:

www.palrx.com Pharmacy Alternatives, Go to Resources, then informational links.

www.krames.com Krames on Demand

www.nlm.nih.gov/medlineplus Medline Plus

My.clevelandclinic.org/health_edge/about_podcast.aspx

www.cdc.org Centers for Disease Control