



Improving and sustaining the quality of health and healthcare for all people with intellectual/developmental disabilities (I/DD) in New Mexico

Nutrition Resources for People with I/DD

People with I/DD are at greater risk

People with I/DD have an increased risk of having or developing nutrition related problems. This risk can come from an underlying medical syndrome. For example, thyroid conditions are associated with Down Syndrome and can also cause nutritional problems. Or the increased risk can come from physical disabilities/limitations, which predispose individuals to medical conditions such as osteoporosis increasing their risk for fractures. And, limited mobility or physical activity increases the risk for obesity. Many people with I/DD also suffer from dysphagia (difficulties with swallowing) and aspiration of food and drink.

Other conditions commonly found in people with I/DD which impact nutrition include: food allergies or aversions; poor feeding skills; partial or total dependence on enteral or parenteral nutrition; inadequate/excessive energy intake; increased or decreased energy expenditure; thyroid disorders; diabetes; growth alterations (failure to thrive, obesity, growth retardation); metabolic disorders; dyslipidemia; dental issues (missing teeth, caries); reflux (GERD); rumination; regurgitation; altered gastrointestinal function; history and/or risk of aspiration; diarrhea; constipation; calcium/vitamin D deficiency; and, medications (anticonvulsants, psychotropic drugs, food-drug interactions, drug-drug interactions) among others.

Helpful Resources

- 1.) First, start with the provider agency providing services to the individual.
 - a) Each agency is responsible for obtaining nutritional services if needed by their client.
 - b) Some agencies have registered dietitians on staff (e.g. ARCA).
- 2) ARCA can also provide nutritional services through secondary freedom of choice (the individual's right to choose authorized service providers).
- 3) In the Northeast region contact Sheryl D. Brewer, RD (P.O. Box 90834, Albuquerque NM 87199)
- 4) Statewide contact the largest provider of nutritional services Global Nutritional Services (GNS) 505-332-8070 (gnsdietitians.com)
- 5) For children on the medically fragile waiver program, his/her case manager can assist in setting up home based nutritional services.

Most of the time, the dietician can come to the individual's home and provide individualized medical nutrition therapy, including trainings to the individual, his/her family or team and development of a individualized menu if needed.

The speech language pathologist (SLP) is also an important part of the team to assist in the assessment, diagnosis, and treatment of swallowing disorders.

A copy of Global Nutrition Services' Tip Sheets on Constipation Prevention Plan; Constipation Treatment for Infants and Children; The Importance of Calcium; The Importance of Calcium to Children; Sources of Dietary Fiber; Nutrition Facts Label; and, Low Fat Cooking Techniques are available on our website: coc.unm.edu/resources/articles.html#GNS

UPCOMING EVENTS & TRAININGS:

Seizures: Causes and Treatments
Carla Fedor, RN CDDN
(CE/CNE submitted)
February 13th, 2015 1-4pm
@ CoC/AFRL

Feeding Tubes,
Lourdes Vizcarra, MD
(CE/CNE submitted)
March 6th, 2015 1-4pm
@ CoC/AFRL

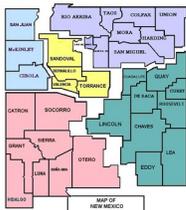
Alternative and Complementary Medicine (CE/CNE submitted)
March 27th, 2015, All day
@ CoC/AFRL

Save the dates

Psychopharmacology
Alya Reeve, MD MPH
April 10th

Agitation and Depression
Alya Reeve, MD MPH
April 17th 10-3

Our trainings are free and open to all. Please visit our website for topics, dates and registration.
<http://coc.unm.edu>



DDSD REGIONAL OFFICES:

The DDSD Regional Offices offer a local resource to help find and access the many services and providers available to individuals with I/DD and their families.

Office Locations/Regional Nurses:
NW Regional Office (NWRO):
2910 E. Highway 66
Gallup NM 87301
866-862-0448
Allison Byrnes, RN 505-326-5784

NE Regional Office (NERO):
224 Cruz Alta Suite B
Taos, NM 87575
866-315-7123
Judith Pierce, RN 575-758-5934

Metro Regional Office (MRO):
5301 Central Ave. NE Suite 1700
ABQ, NM 87108
800-283-5548
Tom Burkross, RN 505-841-5518
Tom Truby, RN 505-841-5536
Anthony Vincent, RN 505-222-6614

SW Regional Office (SWRO):
1170 N. Solano Dr. Suite G
Las Cruces NM 88001-2369
866-742-5226
Randy S. Cahall, RN 575-528-5184
Dora Stewart, RN 575-528-5184

SE Regional Office (SERO):
726 S. Sunset Suite B
Roswell NM 88023
866-895-9138
Maria Sanders, RN 575-624-6100

<http://nmhealth.org/about/ddsd/>

UPCOMING MEETINGS:

Clinical Coordination Group (CCG)
February 9th, 1:30pm @ CoC

Healthcare Decision Resources (HDR)
February 18th, 11:30am @ CoC

DDMI Telehealth Users Group (TUG)
Second Monday of each month
@ 12:00-1:30pm (@ CoC, Telehealth)

¿QUÉ ES?: KETOGENIC DIET CLINIC

An interview with Carla Fedor, RN CDDN Nurse Manager with CoC, about the Ketogenic Diet Clinic and the Ketogenic diet.

What is the Ketogenic diet?

It's a diet that is very low in carbohydrates, low in protein and high in fat. The diet consists of foods such as eggs, cheese and meats. It's an FDA approved treatment for intractable or pharmacoresistant epilepsy.

Is it safe?

Studies have shown that the ketogenic diet is safe when being followed by a team (our clinic has a team consisting of a doctor, a nurse and dietician). We have found that the side-effects that can be associated with the diet are rare.

Does it work?

We see substantial reduction in the severity and frequency of seizures in about 50% of the people who follow the diet, 10% of people stop having seizures altogether, and 30-40% see a meaningful reduction in either severity or frequency.

Is it hard to stick to?

It can be hard if someone is used to eating mainly

carbs and sweets and doesn't like meat, cheese or eggs. It requires supports from family, friends, school and doctors for someone to follow it over the long term.

How can someone get on the diet?

First, they need a referral from their primary care physician or neurologist. Then they would make an appointment with Alfreda Begaye our clinic coordinator. The clinic occurs once a month. When they come in to see us, we will do an evaluation, explain the diet and make sure it is something that they want to try.

We typically start the patient on the diet in the hospital where we can monitor their labs and educate them and their family regarding the diet. It may take up to 3 months for the benefits of the diet to be fully realized. In situations where the diet is helping, they will stay on the diet for up to three years before we try to wean them off of the diet. During that time, we see the patients every three months to examine them, monitor labs and make sure they aren't experiencing any problems.

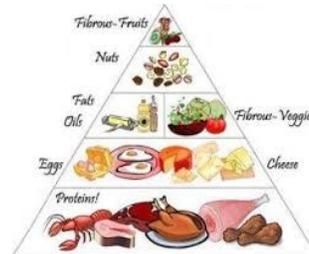
Is it covered by insurance?

Since it is an FDA approved treatment, it is covered. We process the insurance paperwork when

they start the diet as an inpatient in the hospital.

Where can I find out more about the diet?

There is a book called "The Ketogenic Diet" by John Freeman that explains the diet in more detail. There is also a lot of information on the internet including the websites of Johns Hopkins, the Charlie Foundation, Epilepsy Foundation and Matthew's Friends.



The ketogenic diet clinic is a service of the **Continuum of Care** project. For more information or to make an appointment, please contact Alfreda Begaye at (505) 925-2378. There is also a ketogenic diet clinic booklet which provides more information:

<http://coc.unm.edu/clinics/ketogenic.html>

MEDICAL TOPIC EXCERPT:

Title: "Making the most of your Doctor's Appointment"

Presenters: Alya Reeve MD, MPH
and Alfreda Begaye, CMA

[Case Study #1]

Marta is a 35 year old woman who has Cerebral Palsy and a seizure disorder. She lives in a group home with two housemates. In the last 3 days, Marta has become extremely agitated. She has been hitting her head on the left side and has had an increase in her seizure activity. The house staff are concerned with this recent change in behavior and seizures.

- Is this health maintenance, urgent/acute or an emergency?
- What is the next step?

[Getting ready for the appointment]

- What to bring to the Appointment
 - * Patient binder "blue book," "master book"
 - * Logs (sleep, seizure, BM, I&O, etc.)
 - * Health Passport and Doctor visit form

- * Insurance information
- * Proof of guardianship
- * Referral
- Who to bring to the appointment
 - * The patient (usually indicated)
 - * At least one staff who knows the patient well should attend the appointment
 - * The guardian should be present in person or via phone
- Know why the patient is being seen !!!

- Always ask questions

Additional resources:

- There are three related PowerPoint presentations at:

coc.unm.edu/training/presentations.html#featured

- There is a forthcoming training video on this topic which will be available at:

coc.unm.edu/training/video.html#featured

- There are forthcoming updates to our booklet and brochure on "Making the most of your Doctor's Appointment" which will be available at:

coc.unm.edu/resources/brochures.html

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¡¡eNoticias!! Archive Link

<http://coc.unm.edu/resources/NewsletterArchive.html>

Comments/suggestions/recommendations:
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We are on the Web!

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