



MEDICALLY FRAGILE NEWS

7TH Edition

December, 2011

Happy Holidays

Another year has passed by so quickly. It's a busy time of year! I hope this finds everyone enjoying the season and finds everyone happy and well.

There have been a few changes in the Medical-ly Fragile Waiver this year. You should have received a letter letting you know about some of the changes that have occurred to our pro-gram.

One change that was made to the MFCMP parameter guidelines. The changes were made



to the process that de-cides who is eligible for MFCMP services. This change began 9-1-10. As of 9-1-11 all children have been assessed with the new param-e-ters. Look for a ques-tion on the next annual Family Survey regarding

the parameters.

The updated guidelines will provide a better way to assess your child's condition. Your child's doctor and MFCMP case manager will use these guidelines to help de-cide which services are appropriate for your child to receive.

The Rights and Respon-sibilities form which is part of your child's ISP, has been revised by the Family Advisory board, (FAB). We hope you find it more family friendly.

The Family Handbook has been updated and is on the Medically Frag-ile website.

Editor: Lynn Griffin

MFCMP Family Specialist

Special points of interest:

- *Emergency preparedness*
- *How to select a Home Care agency*
- *Flu season tips*
- *Family tidbits*

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THE MEDICALLY FRAGILE CASE MANAGEMENT PROGRAM

In Collaboration with

UNM COLLEGE OF EDUCATION: *The Literacy Mentoring Project*

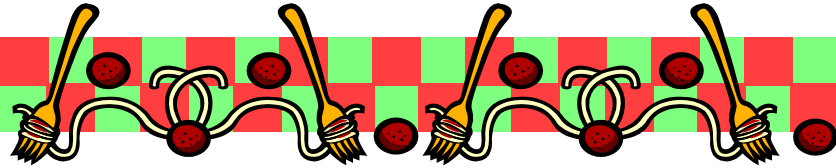
A partnership was developed through a grant received with UNM College of Ed with our program. The students were matched with a youth who have limited prospects of community inclusion and personal fulfillment. These programs have been a way of promoting positive development for this population. They meet at the child's home or foster home two hours a week. Using a family centered approach, the students work in concert with the child's family to explain the literacy program, learn from the families in terms of their child—how their child learns and listens-, gather information about the child and assist the family with new ways to read to the child. A research study has been incorporated to evaluate the participants level of satisfaction and levels of satisfactions gained.



University of New Mexico-Health Sciences Center-
University Centers for Excellence
on Developmental Disabilities
Education, Research, and Services



Las Cruces Family Gathering



Andrew chowing down!

We expanded our Family Networking to another region of the state. We had our first gathering in the southern part of the state at NMSU College of Nursing. We had a nice turn out for our first one. Families made many worthwhile connections.

More to come sometime in the future!



Family Spotlight

The Lowry Family

Hello. My name is Jeannette Lowry. I am a full-time mom. My husband, Chris, and I have been married for twenty years. Chris is an Archaeologist at Fort Bliss in El Paso, Texas. Our son, Sean, is thirteen and every bit the typical teenager. He loves superhero movies (current favorite is X-men: First Class), rock music (current favorite band is the Foo Fighters) and chocolate ice cream. He goes to Sierra Middle School here in Las Cruces and really likes his teachers and his classmates.

Sean was born with Cerebral Palsy and Epilepsy. He has since developed Reflux Disease, Quadriplegic Spasticity and Osteopenia. He is non-ambulatory and must have all of his needs met by one of us. He is also non-verbal but, in recent years, has gained the ability to communicate through the use of an assistive communication device. Through the use of this talker, we have discovered that Sean does not like arts and crafts and has quite a sarcastic sense of humor. Sean has been able to blossom through his talker. He has finally been able to express himself intellectually, which has made him a much happier person in all aspects of his life.

Sean has been our greatest teacher. Because of him, we have truly become a family. Sean is always happy and loves life. He gets over pain, physical or emotional, very quickly. Most of all, he loves us with his whole heart and we love him the same. He is the best person we know.

Best Wishes for a Happy, Healthy Holiday Season

Please note!!!!

The Medically Fragile Case Management office will be closed beginning December 23, 2011, and will reopen on January 3, 2012. Case Managers will be "on-call" for your case management needs on:

December 23, 27, 28, 29, and 30, 2011

The office will also be closed on Monday, January 2, 2012, for New Year's holiday.



Tips for Flu Season-

CDC urges you to take the following actions to protect yourself and others from influenza (the flu):



im-

1. Take time to get a flu vaccine.

- The Center for Disease Control CDC recommends a yearly flu vaccine as the first and most important step in protecting against flu viruses.
- While there are many different flu viruses, the flu vaccine protects against the three viruses that research suggests will be most common.
- The 2011-2012 vaccine will protect against an influenza A H3N2 virus, an influenza B virus and the H1N1 virus that emerged in 2009 to cause a pandemic.
- Everyone 6 months of age and older should get a flu vaccine as soon as the 2011-2012 vaccines are available.

2. Take everyday preventive actions to stop the spread of germs.

- Cover your nose and mouth with a tissue when you cough or sneeze. Throw the tissue in the trash after you use it. Wash your hands often with soap and water. If soap and water are not available, use an [alcohol-based hand rub](#).
- Avoid touching your eyes, nose and *mouth*. Germs spread this way.
- Try to avoid close contact with sick people.
- If you are sick with flu-like illness, CDC recommends that you stay home for at least 24 hours after your fever is gone except to get medical care or for other necessities. (Your fever should be gone without the use of a fever-reducing medicine.) While sick, limit contact with others as much as possible to keep from infecting them.

3. Take flu antiviral drugs if your doctor prescribes them.

- If you get the flu, antiviral drugs can treat your illness.
- Antiviral drugs are different from antibiotics. They are prescription medicines (pills, liquid or an inhaled powder) and are not available over-the-counter.
- Antiviral drugs can make illness milder and shorten the time you are sick. They may also prevent serious flu complications.
- It's very important that antiviral drugs be used early (within the first 2 days of symptoms) to treat people who are very sick (such as those who are hospitalized) or people who are sick with flu symptoms and who are at increased risk of severe flu illness, such as pregnant women, young children, people 65 and older and people with certain chronic health conditions.

IS IT A COLD OR THE FLU?

From the National Institute of Allergy and Infectious Diseases

Symptoms	Cold	Flu
Fever	Rare	Characteristics, high (102-104; lasts 3-4 days)
Headache	Rare	Prominent]
General Aches, Pains	Slight	Usual; often severe
Fatigue, Weakness	Quite mild	Can last up to 2-3 wks.
Extreme Exhaustion	Never	Early and prominent
Stuffy Nose	Common	Sometimes
Sneezing	Usual	Sometimes
Sore Throat	Common	Sometimes
Chest Discomfort, Cough	Mild to moderate; hacking cough	Common; can become severe
COMPLICATIONS	Sinus congestion or ear ache	Bronchitis, pneumonia; can be life-threatening
PREVENTION	None	Annual vaccination; antiviral medicines - see your doctor
TREATMENT	Only temporary relief of symptoms	Antiviral medicines-see your doctor



Caregiver Emergency Plan

Many of us don't think about the what if's...in case of an emergency. We go through day to day life without preparing for these times. We are somewhat fortunate in NM that we generally don't have extreme weather as many parts of our nation. Although, it is better to follow the age-old Boy Scout motto: "Be prepared." It is better to be ready well in advance before a dire situation arises. Your Family Advisory Board has compiled a check

list of suggestions. You may want to considering developing some of your own depending on your family's needs.

DID YOU KNOW?

A birthday candle coated in Vaseline will burn 100 hours?

What will I need?

Try to picture yourself during a disaster and during the three days immediately following it. What might be some of your special medical needs?

People Who Can Help

- Plan with your family, friends, and neighbors. Know who could walk to your home to assist you if other means of transportation are unavailable.
- Discuss your disaster plans with your home health care provider.
- Ask your local fire department if the department keeps a list of people with special medical needs.
- If you depend on electrical power for your medical equipment, notify your local power company. Some companies provide priority service to people with special medical needs.
- Keep a list of people, with their names, addresses, and phone numbers, who can help you if needed.

EMERGENCY CARE LIST

Medications

- * Keep at least a one week supply of your medications at all times.
- * Store your medications in one location in their original containers.
- * Have a list of all of your medications: name of medication, dose, frequency, the name of the doctor prescribing it, and the pharmacy.

Medical Supplies

- * If you use medical supplies, such as bandages, ostomy bags, or syringes, have an extra three-day supply available.

Intravenous (IV) and Feeding Tube Equipment

- * Know if your infusion pump has battery back-up, and how long it would last in an emergency.
- * Ask your home health care provider about manual infusion techniques for power outages.
- * Have written operating instructions attached to all equipment.
- * you or your loved one are injured.
- * A list of the style and serial numbers of medical devices such as pacemakers or special batteries for essential medical equipment.

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EMERGENCY CARE LIST—Con't

Oxygen and Breathing Equipment

- * If you use oxygen, keep an emergency supply for three days or more.
- * Oxygen tanks should be securely braced so they do not fall over. Check with your medical supply company for safety instructions.
- * If you use breathing equipment, have a one week supply or more of tubing, solutions, medications, and other needs.

Follow the old Boy

Scout motto:

“Be prepared.”

Electrically Powered Medical Equipment

- * For all medical equipment requiring electrical power, such as beds, breathing equipment, or infusion pumps, check with your medical supply company and get information regarding a back-up power source, such as a battery or generator.
- * Check with your local utility company to determine that back-up equipment is properly installed.



Emergency Bag

Have a bag packed at all times in the event you need to leave your home. The bag should contain:

- * A medication list.
- * Medical supplies for three days.
- * Copies of vital medical papers, such as insurance cards, Advanced Directive, Power of Attorney, and others.
- * When you leave your home, take refrigerated medications and solutions. Keep ice packs in your freezer if your doctor tells you to keep medications cold.
- * Candles for light
- * A battery powered radio, flashlight and plenty of extra batteries, A first-aid *kit*, *prescription* medicines
- * Food and water. A supply of water (one gallon a day per person per day) store water in sealed, unbreakable containers and replace every six months; a supply of non-perishable food and non-electric can opener, plus any special foods your loved one may require.
- * Extra diapers, wipes, lotion and other hygiene items that don't need water in order to use.
- * Extra wheelchair batteries charged and ready to go.
- * A change of clothing and sturdy shoes for you
- * Extra blankets or sleeping bags.
- * Extra set of keys..

Information compiled from **Colorado Department of Public Health and Environment & Gary Barg—Editor-in-Chief of caregiver.com**

How to make a very cheap and effective heater from simple supplies

- ⇒ 1 full roll of toilet paper, 1 pint of rubbing alcohol, and a empty small tin coffee can w/ lid.
- ⇒ Remove the cardboard center from the roll of toilet paper.
- ⇒ Press the toilet paper roll together and slide into empty coffee can so that the top of the roll is below the top of the rim of the can.
- ⇒ Pour 1 pint of rubbing alcohol into coffee can so that the toilet paper acts as a wick and soaks up the rubbing alcohol.

THE QUALITY MALL

Person center services supporting people with developmental disabilities

The Quality Mall, a place where you can find lots of free information about person-centered supports for people with intellectual/developmental disabilities. Each of the [Mall stores](#) has departments you can look through to learn about positive practices that help people with intellectual/developmental disabilities live, work and participate in our communities and improve the quality of their supports.

END OF LIFE CARE FOR CHILDREN AND ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

3AB727A381D2/0/NINR_PalliativeCare_Brochure_508C.pdf

<http://www.qualitymall.org/products/prod1.asp?prodid=9988>

The for Quality Mall web site is maintained by the [Research and Training Center on Community Living](#) with support from the [National Association of State Directors of Developmental Disabilities Services](#), the [Human Services Research Institute](#) and the [Administration on Developmental Disabilities](#) - U.S. Department of Health and Human Services.
email weste050@umn.edu.

When My Child Dies

We trust that beyond the absence, there is presence
That beyond the pain there can be healing.
That beyond the brokenness, there can be wholeness.
That beyond the anger, there is peace.
That beyond the hurting, there may be forgiveness.
That beyond the silence, there may be compassion.
That through compassion, there may be understanding.
That through understanding, there is love.

Author Unknown

Remembering those who have gone
before us



*May they rest in peace , free of pain
and illness.*

Assistive Technology

1) Enabling Devices

*Products for People with Disabilities
(including a Christmas Catalog)*

50 Broadway

Hawthorne, NY 10532

Phone: 800-832-8697

www.enablingdevices.com

<http://www.enablingdevices.com/>

2) Able Net, Inc.

808 Fairview Avenue North

Roseville, MN 55113

Phone: 800-322-0956

www.ablenetink.com

<http://www.ablenetink.com/>

3) Augmentative Communication, Inc. (Source for Talking Photo Album)

1 Surf Way, #237

Monterey, CA 93940

Phone: 831-649-3050

www.augcominc.com

<http://www.augcominc.com/>

ACI LINKS:

The following websites provide information and services relevant to the AAC community.

[AAC Apps for iPad](#)

[AAC Organizations](#)

[AAC Vendors/Manufacturers](#)

Resources provided by

Suzanne Shaffer RN, CCM

Medically Fragile Waiver Manage

DOH/DDSD/CSB

Medically Fragile Program How to Select a Home Care Agency

Other people can provide you with information and recommendations about home care in your area. However, the decision as to which agency to use belongs to you and your child.

Below are some questions which may help you decide which agency best meets your needs:

- 1) Does the agency have experience caring for children who are medically fragile in their homes?
- 2) Does the homecare agency provide the services that you need? (Registered Nurses, Licensed Practical Nurses, Home Health Aides, Therapists; Speech, Occupational, Physical, and Counselors
- 3) When will their nurses be willing to meet with you before services begin to discuss your child and provide you with more information?
- 4) Is the homecare agency available to take your telephone calls 24 hours a day, seven days a week? Is this a priority for you?
- 5) Is nursing care available on weekends, holidays and nights?
- 6) How will the agency choose the nurses or therapists to care for your child?
- 7) Who does the staffing for the agency? What will happen if your homecare employee is not available to work a shift?
- 8) How are the homecare employees supervised?
- 9) Are caregivers allowed to transport the child?

Agency name	Yes	No

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