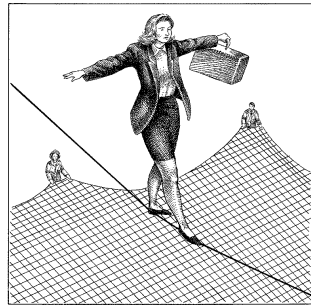


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Emergency Services

Where To Go When You Need Help

Fibromyalgia (FM) is a challenge even under the best of circumstances. When it interferes with patients' abilities to support themselves and their families or pursue their chosen careers, it can be devastating. Thanks to the skills of member/researcher Valerie Hawthorne and the generous assistance lent by scores of FM patients, our Association is now gaining access to valuable resource information on government (federal/state/local) and non-profit programs and services available to persons with fibromyalgia.

Navigating the social service system can be a daunting task to persons with FM who are often already exhausted and battling low self-esteem after spending months or even years seeking a diagnosis. In addition, agencies differ markedly in the quality of their services and the efficiency with which they deliver them. Thus, the more that you can prepare yourself mentally and physically for the ins and outs of the application process, the better your experience will be. Don't let anyone tell you that fibromyalgia is not a "real" medical condition or that you have no right to ask for services, but be prepared to carefully document your financial hardship as well as your illness. In short, be an advocate for yourself.

Financial Assistance

Temporary Assistance for Needy Families (TANF) is the new name given to emergency public assistance after the welfare reform bill of August 1996. Whereas the federal government previously matched state funds dollar for dollar, it now gives Community Block Grants to each state which are then divided into funding for separate programs within the state's department of health and human services (HHS). The TANF program gives cash assistance to families on a time-limited basis. Be aware that while many states use the name "TANF", others may have their own names for programs rendering temporary emergency assistance. Most states dispense such funds on a county basis, so check the government section of your local phone book for the county HHS office nearest you. *Documentation: You may need to bring proof of your health or safety situation; evidence that you are self supporting without any help from relatives (name, address, and daytime phone of landlord or neighbor); proof of any money you are receiving from any source; registration/titles for all vehicles; as well as bank statements, proof of rent/utility payments, photo identification and Social Security card.*

Emergency Assistance is also available from locally based organizations including community action agencies, churches/synagogues, homeless shelters, and domestic violence centers, among others. (It is not always necessary for you to be a member of a church or other house of worship to receive emergency assistance.) Financial help is usually provided to eligible low-income persons to stabilize an immediate financial crisis or help with some other emergency that cannot be managed within a person's own income and resources. It may include: rent or mortgage payments to avoid eviction or foreclosure, utility payments

and deposit assistance, rental deposits, or support that helps an individual secure or maintain employment. Emergency assistance funds are usually limited, and eligibility requirements are very specific. It is possible that a person might apply and qualify but not receive assistance because all available funds have been used. *Documentation: You may need to bring documents showing your total gross income received within a specified period of time. Applicants may also be asked to provide documents that show what the household's crisis is (i.e., lease agreements, eviction notices, utility bills, etc.) and be able to explain and provide proof of events that caused the need for assistance. Documentation such as ID cards, Social Security numbers, birth certificates, and residency information are also usually necessary to determine eligibility. Each agency may require additional information.*

Unemployment Insurance (UI) is a type of compensation available after you have lost a job. It provides regular cash payments which provide financial support while you look for another position. UI does not apply to jobs you have left without a termination. The amount of the payments you receive and their duration usually depends upon how much you earned in wages in the past. Contact your state unemployment office as soon as you have lost your job to expedite receipt of UI benefits. *Documentation: You may need to bring paperwork showing your latest place of employment and the reason your job was terminated. Also, bring documentation of any extra income you receive, including subcontracting, pension plans, etc. In case of an inquiry, keep a job log that documents on a weekly basis your attempts to find work.*

Social Security Disability Insurance (SSDI) benefits are paid to workers under age 65 when earnings are lost or reduced due to disability. You may be considered "disabled" if you have a physical or mental impairment which (1) prevents you from working, and (2) is expected to last for at least 12 months or result in death. Before a worker can apply for Social Security benefits, (s)he must have credit for a specified amount of work. The exact amount of credit depends upon the worker's age. For additional information on filing procedures and requirements, contact your local Social Security Administration office in the U.S. government section of your phone book or visit their website located at www.ssa.gov. SSDI information packets for fibromyalgia patients are also available from our Association, as well as several other large fibromyalgia organizations. Additional information is available on the Web at: www.disabilityassistance.com (disability information for FMS/CFS) or www.ssas.com (Social Security Advisory Service). If you need to find an attorney to help you file an SSDI application or an appeal, contact the National Organization of Social Security Claimants' Representatives (NOSSCR) at: 800/431-2804 or visit its website at: www.nosscr.org. The website also contains frequently asked questions and resource information for SSDI. Note: Most private attorneys and others who represent claimants accept cases on a contingency fee basis so no fee is charged unless the claim is successful.

Supplemental Security Income (SSI) makes monthly payments to people who are aged, disabled, or blind and have limited income and resources (assets). To receive SSI payments on the basis of disability or blindness, you must meet the Social Security Administration's definition of "disabled" or "blind", have limited income and resources, and be a citizen of the U.S. or its territories. Social Security work credits are not necessary to obtain SSI payments, so you may be eligible for SSI even if you have never worked. It is also possible to receive SSI benefits and qualify for Social Security Disability, if you are eligible. States may add to the federal SSI payments and provide Medicaid, food stamps, and various other social and rehabilitation services. For information about SSI, contact your local Social Security Administration office. *Documentation: You may need to bring proof of age, medical records, or other documents which verify your disability; the names and addresses of doctors, hospitals, and clinics that have provided treatment and care; information about income and resources; and documents which prove citizenship (i.e., birth certificate, driver's license, and Social Security card).*

Workers' Compensation is a form of insurance which many employers are required to carry by the federal government. It usually covers falls, accidents, and injuries (including repetitive-strain injuries) which arise out of employment and occur during the course of employment. It may also cover certain occupational

diseases. Although regulations vary from state-to-state, benefits may include temporary disability payments (either partial or total), permanent disability payments (either partial or total), medical/hospitalization benefits, some level of wage reimbursement, and vocational rehabilitation. Claims are generally processed and adjudicated by state Workers' Compensation offices/commissions while benefits are paid by employers or their insurance carriers as directed by the state. For information on filing procedures and available benefits, contact your nearest state Workers' Compensation office/commission or visit its website.

The Good Deed Foundation: The CFIDS Association of America recently announced the existence of the Good Deed Foundation, a 501(a)(3) nonprofit organization that provides financial assistance to persons with chronic fatigue syndrome (CFS/CFIDS). Award applications must be completed, and notarized by the requesters and their health providers. Applications are reviewed and awards given on a quarterly basis according to need. The Good Deeds Foundation has three major programs: financial assistance to the ill/disabled ("Wishing u Well"), the encouragement of a good deed ("The Bridge of Hearts" program) and the "Fountain of Wisdom" program, where the foundation provides tuition assistance for parochial schools or private schools of any religious denomination. To request an application write: The Good Deed Foundation, Inc., 618 Anderson Circle, #211, Deerfield Beach, FL 33441. (Enclose a self-addressed, stamped envelope.)

Food/Meals

Food Stamps are coupons that can be used the same as money to buy nutritious food. Food stamps comprise only part of the food budget, however, so shoppers must spend some cash along with food stamps to buy enough food for a month. To apply, contact the nearest office of your state's health and human services department. The application process usually takes at least 30 days. *Documentation: You may need to bring proof of income (paycheck stubs, award letters for all benefits already received); utility bills; rent/mortgage receipts; medical bills; current bank account statements; vehicle registration(s) and statements of any money owed on motor vehicles; and a photo identification, driver's license, and birth certificate.*

Community-Based Food/Meals Programs may include "Meals on Wheels", "Channel One", or "Brown Bag" programs which provide meals or a bag of groceries on a regular basis to help meet food needs. They may also include local food banks or food pantries run by local agencies or churches/synagogues. In addition, some grocery stores or food cooperatives offer free delivery and lower (sometimes wholesale) prices. Joining a community garden may provide low cost and healthy products. Depending on the garden, use may be free or require a small users fee. "FISH" (Food Self-Help) programs may pay cash for a "Good Samaritan" deed. Check the availability of these resources by looking in the phone book, calling directory assistance, or contacting local social service agencies or houses of worship.

Housing/Rent

State Programs: These include not only Section 8 housing and emergency shelters but also other benefits such as: Eviction Prevention Programs (which assist low and moderate-income residents who are at risk of losing their homes or becoming homeless due to inability to pay rent) and Security Deposit Assistance (which provides the equivalent of one month's rent to pay a security deposit for a new apartment). Other state programs to look for are: Home Investment Partnership Programs such as U.S. Department of Housing and Urban Development (HUD) grants/loans awarded on a competitive basis to eligible individuals, developers, and housing authorities for affordable housing activities; Mutual Housing Associations (loans and grants provided to associations of low-and moderate-income tenants who participate both in the operation and management of their housing); and Small Communities Development Block Grant programs (HUD grants awarded to communities with fewer than 50,000 people for housing, economic development, and community facilities). One Association member recently informed us that some states offer disabled

persons rent on a sliding scale in HUD housing. She noted that it helps to get a handicapped placard from your Department of Motor Vehicles for your doctor to fill out. It not only paves the way for disabled housing, but it also provides easy access to stores when you are alone or disoriented by FM symptoms.

Federal Loans: If you have a disability and need to adapt your home to your needs, you may be eligible for a Title I Home Improvement Loan insured by HUD. The loan can be used to remove architectural barriers, hazards, or inconvenient features in the home. Improvements can be handled on a do-it-yourself basis or through a contractor. The loans are applied for through banks or other lending institutions. HUD insures the lender against possible loss. For further information contact your nearest HUD office, or write to: The Assisted, Elderly, and Handicapped Program, Department of Housing and Urban Development, 451 7th Street, S.W., Room 6116, Washington, DC 20410. In addition, low income individuals may be eligible for loans from the Farmers Home Administration to purchase or repair a home which is located on a farm or in a very rural area. For more information, write to: Farmers Home Administration, Department of Agriculture, Washington, DC 20250.

Federal Rent Assistance: Low income persons (including those with disabilities) may be eligible for housing assistance payments from the U.S. Department of Housing and Urban Development. Payments are made directly to the owners of rental units by HUD to make up the difference between the (HUD) approved rental amount and the amount the tenant is required to pay. Tenants pay an average of 30 percent of their adjusted income (gross income less certain deductions and exceptions). Rental assistance payments under this arrangement are not considered additional income to the tenant who is also eligible for Supplemental Security Income payments from the Social Security Administration. For information on rent assistance or housing programs benefiting people with disabilities, write: Special Advisor on the Handicapped, U.S. Department of House & Urban Development, Room 19184, Washington, DC 20410.

Utilities

LIHEAP: Almost every state government department of health and human services offers this program. It is a combined heating and cooling assistance program designed to help qualified, low-income individuals pay their utility bills. This federal program is operated throughout the year by Community Actions Programs and a small number of community-based organizations. *Documentation: You may need to bring copies of your gas and/or electric bills. You may also be asked to provide proof of income for the last 30 days, including copies of pay stubs, award letters, and/or your Social Security number. Some states offer weatherization services to help cut down on monthly heating bills.*

State Utility Company Services: Some state utility gas companies reduce their monthly bills on an ongoing basis. Contact your local utility company to determine if this program is available. Be aware that you may have to present medical documents. You can also sign up in some states for equalizer payments where your last year's utility bill is averaged to equal per month payments. A special rate discount is used that may only save you \$3-\$10 a month, but that can add up over time.

Medical Assistance

Medicaid (Medical Assistance Program) is a joint federal/state program which provides physical and related health care services to low income persons. Individuals with disabilities may be eligible for Medicaid on the basis of income. Because eligibility is determined by your state program of public assistance on the basis of broad, federal guidelines, there are geographic differences between eligibility requirements and the types of services covered. Generally, a person may be eligible for Medicaid if (s)he is receiving welfare,

other public assistance benefits, or Supplemental Security Income or is blind or disabled. Medicaid services are available in all states. Individuals with higher incomes may be eligible for Medicaid Supplemental Medical Care Assistance, or their children may be eligible if medical expenses exceed a given percentage of their annual income. Information on Medicaid is available from your local or state welfare or public assistance office. If you cannot get information locally, write to: Health Care Financing Administration, Inquiries Staff, Room GF-3, East Lowrise Building, Baltimore, MD 21207.

Medicare: This health insurance program is designed to serve everyone over 65 years of age as well as people with disabilities under 65 years of age who have been approved for Social Security disability benefits for a total of 24 months or who need dialysis treatments or a kidney transplant because of permanent kidney failure. The program is not based on income and is available regardless of financial need. Medicare has two parts: Part A: Hospital insurance at no premium that helps pay for care while in the hospital and for related health care services after leaving the hospital. Certain deductibles and coinsurance amounts apply. Part B: Voluntary medical insurance at a monthly premium that helps pay doctor bills and other approved medical services. More information about Medicare is available from your local Social Security Office, or by writing to: Health Care Financing Administration, Inquiries Staff, Room GF-3, East Lowrise Building, Baltimore, MD 21207.

Clinic of Angels is a non-profit organization dedicated to providing medical treatment to less financially fortunate members of the chronic fatigue syndrome (CFS) and fibromyalgia communities throughout the world. The goal of the Clinic of Angels is to reach out to severely financially strapped people with CFS/FM so that they may significantly improve their quality of life by receiving treatment and prescribed medications from recognized CFS/FM doctors that they cannot now afford. Board members of the Clinic of Angels validate and prioritize requests for medical treatment and negotiate with recognized medical specialists in a patient's area. The Clinic will also negotiate with mail-order pharmacies to obtain prescribed medications. For details, contact: Clinic of Angels, 5100 Burchette Road, Suite 1003, Tampa, FL 33647. Website: www.geocities.com/HotSprings/Chalet/1835/.

Community Health Clinics: Many communities offer clinics where services are available for free or for a substantially reduced cost. Check your local phone book or contact your nearest state health and human services office.

Medications

Pharmaceutical Company Programs: The pharmaceutical industry has a long tradition of providing prescription medicines free of charge to physicians for patients who cannot otherwise afford them. For a listing of pharmaceutical companies offering programs along with application information, visit the website of the Pharmaceutical Research and Manufacturers of America (PhRMA) at www.phrma.org/patients/index.html. Their *1999-2000 Directory of Prescription Drug Patient Assistance Programs* can be downloaded from this site. Or write: PhRMA, 1100 15th St., NW, Washington, DC 20005. Phone: 202/835-3400.

The Medicine Program: This nationwide organization was established by volunteers for patients unable to afford the cost of their prescription drugs. The primary requirements for prospective applicants are: (1) having no insurance coverage for outpatient prescription drugs; (2) not qualifying for a government program which provides for prescription medications (i.e., Medicaid); and (3) having income so low that purchasing medications at retail prices incurs a hardship. For information, contact the Medicine Program at: P.O. Box 515, Doniphan, MO 63935-0515. Phone 573/996-7300, or visit its website: www.themedicineprogram.com/info.html.

Other Medications Assistance: If you cannot afford prescription medications, check with your physician. (S)he can often provide you with free samples in the office. Many community health clinics also provide medications at reduced prices.

Transportation/Travel

Local Transportation: Some states offer a local transportation program for persons who are disabled. For more information, call the information/general assistance numbers at your local bus stations, train stations, and airports. In addition, the Metropolitan Transit Authority in many cities offers special buses and other services such as discount fares, "reserve-a-ride programs, or regional ride sharing. Medicaid can also offer free transportation to your doctor's office. For details on available services, check with your local Metropolitan Transit Authority.

Travel: Recently, the federal government has stepped up its efforts to make transportation systems more accessible to disabled travelers.

Air Travel: The Federal Aviation Administration (FAA) now requires each U.S. airline to have a FAA-approved, national company policy on accessibility/services to individuals with disabilities. These policies vary by airline, so make your special needs known when arranging reservations. For details, contact individual airlines directly. Also helpful is the publication, *Access Travel: A Guide to Accessibility of Airport Terminals*, available from The Consumer Information Center, Pueblo, CO 81009.

Travel By Rail: Amtrak, the country's major passenger rail system, has announced that it will add to its system only new cars fitted with special facilities for people with disabilities. Information on accessibility of trains and stations and assistance available to passengers who are disabled or elderly may be obtained from an authorized travel agent or by calling Amtrak at 800/USA-RAIL. Travelers with disabilities who have a card or physician's letter showing disability are allowed a 25 percent discount on round trip travel by Amtrak with the exception of certain holidays. Amtrak also has a brochure, *Access Amtrak*, for travelers with disabilities. To request a copy, write: Amtrak Distribution Center, Itasca, IL 60143.

Personal Support Services

Adult Services: Some states provide home care services to eligible people with disabilities. Social workers coordinate planning and management of services to help clients stay independent and in the community. Services can include homemaker, housekeeper, adult companion, day care, and home delivered meals. Income/asset eligibility applies.

Personal Care Assistant: Some states provide grants to people with disabilities for the purpose of retaining personal care assistants needed to enable the person to work. Income eligibility applies. Sometimes a Medicaid waiver will allow payment for a personal care assistant.

Friendly Visitor programs provide trained volunteers to make regular home visits to isolated elderly adults who are living in their own homes, and in some instances, to provide transportation for shopping and medical appointments.

Table 1: Things To Remember When Seeking Benefits

- 1) When you walk into your local county office to obtain services, be prepared with needed documentation. Keep organized files of all of your records: doctor visits (including a letter stating your illness, medical bills, etc.), benefits (award letters and other documentation), employment (proof of income or unemployment), financial (checking and savings account bank statements), vehicle (registration), rent or mortgage (receipts), utility bills documentation, and other miscellaneous documentation, such as your photo identification, your Social Security card and your birth certificate. Always keep your originals.
- 2) Even when talking on the phone, write down the date and time of the call, the name of the organization, the name and title of the person you talked to, and a summary of what was discussed and promised, including the timeline. Get a supervisor's name if possible. During the phone call, try to confirm in detail the process you were told to follow to obtain your benefits, and the timeline you were told. Immediately write this information after the phone call and put it in the appropriate folder. If possible, write a confirmation letter and include a copy in your records.
- 3) Create forms to expedite processes. For example, if particular information is repeatedly required from your doctor, create one form so it's easier for the doctor to fill out.
- 4) Persistence gets the best results. Make weekly phone calls and ensure agency contacts remember your name and your situation.
- 5) Don't do it on your own. Be very persistent with your doctor and other involved personnel on your end to make sure they all follow through and are advocates for you.
- 6) Be thorough. Try to get benefits from as many sources as possible as backup. Keep a log to keep track and detail your progress.

Table 2: Other Useful Sources of Information

First Call for Help: a 24-hour, statewide information and referral service for health and human services throughout a given state. It not only provides emergency assistance contact information (i.e., rent, food, utilities, phone) but can also provide other information such as mentoring or after-school programs. Most states provide this service but sometimes under different names. Call your local United Way office (they usually sponsor these programs), or dial your general phone information number (i.e., 411) and ask for information and referral services for emergency assistance.

Government Crisis Centers: usually listed in phone book. Also look under "Fuel Assistance", "Information and Referral", "Social Services" and "In-Home Services". Sometimes Social Service agencies pay rent, gas, water and electric bills in the form of a loan. Occasionally, you can pay back this loan by providing community service rather than money.

Social Workers: phone area hospitals and local universities to locate social workers. These professionals tend to be knowledgeable about programs providing emergency financial assistance in your area.

Federal Information Center: Phone 800/688-9889 to find any federal program.

State websites tend to be listed in the following format (or do a search using www.searches.com): For example, for the state of Iowa: <http://www.state.ia.us>. (Replace the letters in bold with your state two-letter abbreviation). You can also find health service information in any state at: www.healthfinders.gov.

Local Library: These usually have one or more books containing city domestic resource listings. They also usually have a listing of volunteer organizations that will help with transportation, delivery of food, etc.

Directory of Disability Information: Phone: 800/346-4800

National 24-Hour Domestic Violence Hotline: Phone: 800/799-7233 or 800/787-3224 TDDY

National Coalition Against Domestic Violence

PO Box 18749

Denver, CO 80218-0749

Phone: 303/839-1852, Fax: 303/831-9251

Website: <http://www.webmerchants.com/ncadv>

Grass roots coalition of battered women's service organizations and shelters. Supplies technical assistance and makes referrals on issues of domestic violence.

National Suicide Prevention Hotline: 800/SUICIDE

American Society of Suicide Prevention and Crisis Centers Headquarters: Phone: 202/237-2280

U.S. Department of Housing and Urban Development (HUD) Office of Fair Housing and Equal Opportunity: Phone: 800/669-9777

Christmas in April USA

1536 16th St., NW

Washington, DC 20036-1402

Phone: 202/483-9083, 800/473-4229. Fax: 202/483-9081

Nationally based, volunteer efforts to repair and rehabilitate homes of low-income, elderly, and disabled homeowners in one to two day labor-intensive operations. Active in 620 cities.

Rural Housing Service

1400 Independence Ave., SW, #5014

Washington, DC 20250

Phone: 202/690-1533, Fax: 202/720-4323

Website: <http://www.rurdev.usda.gov/rhs/index.html>

Offers financial assistance to apartment dwellers and homeowners in rural areas.

Local Independent Living Center (ILC): Good source of information, referral, and advocacy on housing issues, home help, employment, education, equipment, and financial assistance. ILCs are private, non-profit organizations run by and for people with disabilities. To find your local ILC, contact ILRU at 713/520-0232, or 713/520-5136 (TTY), Fax: 713/520-5785, Website: www.bcm.tmc.edu/ilru/ilnfaqs.html. Email: ILRU@ilru.org.

National Council on Independent Living (NCIL)

1916 Wilson Boulevard, Suite 209

Arlington, VA 22201

Phone: 703/525-4153 (TT), E-mail: ncil@tsbbs08.tnet.com

NCIL is a national membership association for independent living centers and supporters. It disseminates information about independent living matters and relevant legislation through its membership network.

NCIL can provide referral to a local program to consumers, current practical information to professionals, and advice to persons interested in starting an independent living center.

Independent Living Research Utilization (ILRU)

2323 South Shepherd, Suite 1000

Houston, TX 77019

Phone: 713/520-0232, Fax: 713/520-5785

E-mail: ilru@ilru.org

ILRU is a national resource center for independent living. It produces resource materials, develops and conducts training programs on independent living issues, provides technical assistance/consultation to independent living centers, and more. Publishes *Directory of Independent Living Programs* which lists programs by state (\$10 prepaid). Contact ILRU for free referral to projects near your community. Write for a complete publications list.