

# Family Care

**Terry Lynch**, Independent Living Consultant

## Introduction

The purpose of this chapter is to help you understand what the Family Care program is, who is eligible for it, and how to obtain Family Care services and assistance. It is also to help you understand your rights in the Family Care program and where to get help protecting these rights.

## What is the Family Care Program?

Family Care is a state and federal funded long-term care program which began operating in several counties in 2000. Long term care (LTC) refers to various kinds of help people with disabilities and frail elders need in order to be as independent as possible and experience a positive quality of life. LTC includes helping people remain in their homes by providing services such as assistance with bathing and dressing, or with preparing meals and managing their checkbooks. It refers also to assisting people to participate in community life, including meaningful work, by providing them with support such as attendant care and transportation. LTC also can mean residential care outside one's home, for instance in group homes or nursing homes. *(See pg. 209 for more on LTC services provided by the Family Care program.)*

**Family Care website**  
[www.dhfs.state.wi.us/LTCare](http://www.dhfs.state.wi.us/LTCare)

As of the date of publication of this guide, Family Care (FC) is in its developmental stage. Consequently, it will be available to people in only a few Wisconsin counties in its first several years. After a period of learning in these "pilot" counties, the state plans to gradually expand Family Care to the entire state. To find out if FC is available where you live, contact your county Department of Human Services (also called Department of Community Services), or call the Wisconsin Coalition for Advocacy, 1-800-928-8778.

Currently, the state may contract for FC only with counties, tribal organizations or family care districts formed by counties. At some point, other kinds of organizations may be eligible to operate FC at the local level, but probably not before 2003.

## Family Care Program Goals

FC is meant to be more than just another "long term care program". It is intended to reform the way LTC is provided in Wisconsin. Some of its most important reform goals are to:

- create an absolute right (entitlement) to FC services for those most in need. In other words, its goal is to end waiting lists for entitled persons *(see pg. 206);*

Sec. 46.2805(4), Wis. Stats.  
HFS 10.36, 10.43, and 10.44(f),  
Wis. Admin. Code



- replace the confusing and restrictive current state-funded and county-operated LTC programs with an uncomplicated, easily accessed “Family Care Benefit”;
- ensure that LTC decisions about an individual’s life will be made by that person or by those who are closest to and know the most about that person;
- provide people who are eligible for FC with a broad choice of supports and services, including the choice to control one’s own budget and plan of care; and
- maximize support from one’s family, friends, neighbors and the community in which that person lives.

## The Aging and Disability Resource Center

Each county or tribal FC program is to provide all residents of the FC service area with assistance from an Aging and Disability Resource Center (RC). The RC serves as a gateway to the FC program. One of its primary functions is determining eligibility for FC. However, RCs are to do much more than that. They are required to be actively involved in helping people throughout the service area to avoid or limit problems that require LTC. They are to be welcoming and convenient places where you can get information, advice, and access to a variety of LTC services, whether or not you are eligible for FC. The RCs are required to provide:

- **Elder Abuse and Adult Protective Services:** The RC is required to identify those who need protection from elder abuse or who need adult protective services and provide those services directly or through a contract with another agency.
- **Transitional Services:** The RC is to provide services which assist children with physical or developmental disabilities to transition from the children’s system to the adult long-term care system.
- **Prevention and Early Intervention Services:** The RC is to develop a plan to help prevent or limit the severity of long term care-related problems for residents of its service area.
- **Emergency Response:** Emergency calls to the RC will be received and responded to 24 hours a day, seven days a week.
- **Long-term care options counseling:** The RC is required to offer various kinds of counseling and problem-solving assistance related to long term care at locations and times convenient to anyone in its service area who is looking for or who needs LTC services. A major RC responsibility is to help older people and

Sec. 46.283(3), Wis. Stats.  
HFS 10.23, Wis. Admin. Code

people with disabilities live with dignity and maximize independence and quality of life.

**Eligibility for Medicaid,  
SSI, Food Stamps**

Sec. 46.283(k), Wis. Stats; HFS 10.23(3),  
Wis. Admin. Code

The RC will also determine eligibility for the Medicaid Program, Supplemental Security Income, and the federal food stamp program.

The RC must provide aids, assistive devices and make other accommodations so that people living in its service area can benefit from its services.

Note: Some counties which do not provide Family Care are operating RCs. Be sure to check whether there is one in your county.

## Help from Advocates

As you read the rest of this chapter, keep in mind that the law requires RCs and Care Management Organizations (which plan and arrange for needed FC services) to provide you with assistance from advocates with all aspects of FC and to cooperate with these advocates. At any time, you have the right to ask for help either from internal advocates (staff who work for these agencies) or from advocates who are independent of the FC system.

### Internal Advocates

**Benefit specialists**

Sec. 46.283 Wis. Stats.  
HFS 10.23(2) and HFS 10.23(2)d),  
Wis. Admin. Code

RC benefit specialists are internal advocates. These specialists offer assistance which includes: providing information about and help applying for benefits under public and private programs, including Medicaid, SSI, food stamps and Family Care; guidance on self and family advocacy; and negotiation with CMOs, providers, or the state regarding disputes over LTC services.

These specialists will also assist you in filing complaints and grievances related to the FC program or other programs and benefits such as Medicare and Medicaid; represent you in administrative hearings and other grievance proceedings; and refer you to attorneys for representation in court proceedings.



*If you are having trouble understanding how to apply for FC or other services, or simply feel that you are not getting the cooperation you need at the RC, ask for assistance from the benefit specialist. This person is there to help you cut through the red tape.*

**CMO member advocate**

CMOs are to designate an employee as a “member advocate” who will report directly to top CMO managers. At a minimum, the member advocate is to follow up with new enrollees within 2 months of enrollment, assist members with issues and concerns, and assist in ensuring quality CMO services to members.

Sec. 46.283(4) and 46.287(2), Wis. Stats.  
HFS 10.23(2) and HFS 10.57,  
Wis. Admin. Code

## Independent Advocates

The legislation establishing Family Care also establishes a FC Independent Advocacy (FCIA) System. This system is independent of the state and county agencies which administer FC, and is required to provide advocacy to potential or actual FC consumers, their families or guardians. FCIA services include: information, assistance and training on how to obtain FC or other services; help filing complaints, grievances and appeals; and various kinds of direct advocacy help, including negotiation, mediation and assistance with problems related to the interpretation of federal and state law and regulations. FCIA staff also will provide representation in hearings and legal matters related to the FC program.

### Protection from retribution for seeking help

The Wisconsin Department of Health and Family Services (DHFS), RCs and CMOs will cooperate with any advocate selected by a client. "Cooperate" means to provide any information related to the client's eligibility, entitlement, cost sharing, care planning, care management, services or service providers to the extent that the information relates to the matters in which the client is receiving advocacy assistance. It also means that a client who requests assistance from an external advocate is to be assured that s/he will not be subject to any form of retribution from the county for seeking this assistance.

To reach the FCIA system, call the Wisconsin Coalition for Advocacy at 1-800-928-8778.

## Who is Entitled to Family Care?

This section will take some work to get through, but it will be worth it. You need to understand it in order to know if you or someone you care about can get help from the Family Care program. *(See page 212 for information on how FC can assist private pay individuals.)*

In those counties where Family Care is available, some people have an entitlement to FC. These people:

- are at least age eighteen;
- are residents of counties or tribal service areas in which FC is available. They may also be eligible if they live either in or outside the FC service area in a LTC residence, such as a nursing home;
- have a physical disability, or are frail elders, or have a developmental disability and live in a county in which a FC program began operating prior to July 1, 2001;
- are financially eligible for the FC program which means they are eligible for the Medicaid program or would qualify for Medicaid

Sec. 46.286, Wis. Stats.  
HFS 10.30 and 10.33, Wis. Admin. Code

### Financial eligibility

except for financial or disability criteria, and the projected cost of their service plans (*see page 208*) exceeds their gross monthly income, plus 1/12 of their countable assets, minus deductions and allowances permitted by DHFS; and

### Functional eligibility

- have long term care needs which are likely to last more than 90 days and which make it necessary for the person to have someone with him/her much of the time.

People are also entitled to FC who do not need as much daily assistance but are at risk of losing their independence and need adult protective services; or qualify for Medicaid; or they are living in a nursing home; or are receiving county long-term care services at the time FC starts operating in the county or tribal area.

### Eligibility without entitlement

Sec. 46.286(3), Wis. Stats.  
HFS 10.36, Wis. Admin. Code

A person who does not meet the above entitlement criteria may still be eligible for FC, but might have to be placed on a waiting list until FC funds are available. For instance, if you don't require as much assistance with your long-term care needs as many others in the FC service area do and you are not eligible for Medicaid, you could be asked to wait to receive services until funds become available to serve people at your level of need, or until you establish eligibility for Medicaid. Ask the RC to provide you with its waiting list criteria.

## Family Care Entitlement and Eligibility Determination

Sec. 46.283(3)(b)and(e), Wis.Stats.  
HFS 10.23, Wis. Admin. Code

RCs are responsible for "screening" people to determine entitlement and eligibility. The RC must offer both a financial eligibility screen and a functional eligibility screen. The functional screen determines your level of need for assistance.

## Right to move into the community People in Nursing Homes or Other LTC Facilities are Included

FC gives everyone a choice regarding where and how they live, including people who are already living in a nursing home or LTC residence when the program begins. RCs and LTC facility staff are required to inform all residents of the FC benefit and offer them the opportunity to be screened for FC eligibility. Some people living in LTC facilities may be able to move to residences which they find preferable to their current living situation.

Secs. 486.283(4)(e) (f) (g), 50.033(2r)(2s),  
Secs. 50.034, 50.035 and  
50.04(2)(g)(h)(m), Wis. Stats.

When people are considering moving to a nursing home or other LTC facility, they must first be referred to their RC for a FC eligibility determination. People who will pay privately for LTC facility services are not required to be screened for eligibility, unless they are likely to become eligible for Medicaid within six months.



Sec. 50.36(2), Wis. Stats.  
HFS 10.72, Wis. Admin. Code

## Hospital Referral Responsibilities

Where FC is available, before discharging a patient who is 65 or older, or who has a physical disability or developmental disability, the hospital is required to refer that person to the RC for assistance.



*Hospitals sometimes wait until shortly before discharge to help patients plan for how they will manage their LTC needs when they leave. Patients or their representatives should take it upon themselves to be sure the RC is contacted as soon as they are admitted to the hospital.*

## Obtaining Family Care Services

### Enrollment

#### Care Management Organization

Sec. 46.284(3), Wis. Stats.  
HFS 10.43 and 10.44, Wis. Admin. Code

Once it has been determined that you may participate in Family Care, you must enroll in a FC Care Management Organization (**CMO**). Once you enroll, you become a “member” of that CMO. CMOs are responsible for providing the full range of LTC services needed by its members. The CMO will provide you with a specialist called a “care manager” to help you plan, and then to help you make the plan work. Since the care manager is to be your partner and your advocate, s/he needs to be someone you like and get along with.

#### Culturally appropriate

Sec. 46.284(3), Wis. Stats.  
HFS 10.41 and 10.43,  
Wis. Admin. Code

If you are a member of a minority group, or your primary language is not English, the CMO is obligated to communicate with you in your primary language, and arrange with you for services that are appropriate to your beliefs and practices. You have the right to be assisted at all times by an interpreter when you communicate with FC staff.



*Each CMO will have a process for helping you change care managers if you wish to.*

### Assessment and Development of an Individualized Care Plan

All FC enrollees are to be full partners in figuring out what kind of service plan works best for them. One of your most important rights in Family Care is your right to make the choices you feel are best for you. The CMO care manager is required to help you understand your full range of choices, and then to help you, or someone you trust, to make planning decisions based on the options you like best.

The process you will go through includes:

#### Assessment of needs/preferences

Secs. 46.284(4), and 46.27(a)(c), Wis. Stats.  
HFS 10.41(2) and 10.44, Wis. Admin. Code

- an assessment of your needs, your preferences and also of your skills and capabilities. The care manager is required to find out who is in your life who is either helping you with your LTC needs or could help you if they were asked to.

#### Individualized service planning

Sec. 46.282(4), Wis. Stats.  
HFS 10.44 and 10.55, Wis. Admin. Code

- CMO staff will then work with you to develop an individualized service plan (**ISP**) which fits your needs and circumstances. The plan must also identify the personal outcomes you wish to

experience as a result of participating in Family Care. *(See pg. 210 for more information on these outcomes).* You or your representative(s) are to participate as full partners in the development of this plan, if you wish to. Your wishes and needs are to have priority in developing the ISP.

*(For information on self-management of service funding see pg. 219 in Self-Determination chapter.)*

## Choosing where you Live

One major planning choice is where you want to live. The CMO must assist FC members to live where they prefer unless this living arrangement will threaten member health and safety, or unless the costs of this arrangement outweigh the benefits to the member.



### Choice of alternatives to nursing homes

HFS 10.55(1)(f)1., Wis. Admin. Code

*No one “needs” to live in a nursing home. What people need is differing levels of LTC and health care. Many people in nursing homes could live elsewhere if they had skilled professional assistance to make that choice. CMOs are there to provide that assistance; so is the Independent Advocacy System.*

Sometimes a CMO member may be required to live in a nursing home or other place where s/he does not want to live during short-term treatment or rehabilitation. Another allowable reason is to make sure the place the person has chosen will be a safe place to live. In these cases, CMO staff must actively work to return the person to his/her home, or the next most acceptable alternative.

In working out your ISP, keep in mind that you have a right to a wide variety of services. Some of them include: adaptive aids; communication aids; home health and personal care services; home modification; emergency services; supported employment; transportation; respite; and services in LTC residential facilities.

## Choosing Flexible Services

One of the most important aspects of FC services is that there is no set “list” that you must choose from. The care manager is responsible for being creative in helping you plan the services that are unique to your needs and strengths. The ISP is to be flexible and to fit services to what you need to live your life as well as possible. If it is possible to work out a plan where most of your help comes from family, friends and neighbors, and that is what you would like, the CMO is required to help you do that. It is also important to remember that you and your care manager must balance the needs and desired outcomes identified in the assessment with reasonable cost, availability of services and the ability of the CMO to develop alternative services and living arrangements. Regardless of where you live, including rural areas, CMOs must provide necessary and geographically accessible services.

### Service flexibility and cost-effectiveness

HFS 73.06, 73.08, 10.41, 10.43 and 10.44 (f), Wis. Admin. Code

### Services in rural areas

Sec. 46.284(3), Wis. Stats.  
HFS 10.41 and 10.43, Wis. Admin. Code



**Reassessment of needs**  
HFS 10.44, Wis. Admin. Code

Keep in mind that you may change your original ISP if it is not working out for you. The CMO is obligated to periodically work with you to reassess your needs and how best to support you. A reassessment is required immediately if there is a significant change in a member’s health or living situation, or there are other major life events which affect the member’s needs.

**Right to Timely Services**

HFS 10.55(1)(d)., Wis. Admin. Code

A person enrolling in FC has the right to services and support items provided as quickly as necessary to protect his/her health and safety. The CMO has up to 60 days to complete an individualized service plan for non-urgent services. You and your care manager will set timelines for the receipt of services you decide on in the ISP. The CMO must ensure that you receive those services according to these timelines.

**Consumers can Manage their Own Services and Supports**

Sec. 46.284(4), Wis. Stats  
HFS 10.44, Wis. Admin. Code

One choice you have is to be your own care manager and to be in charge of managing your services. The CMO must have a process for helping you understand this choice. If it is a choice you want to make and that you can manage, CMO staff will help you set it up. They also will help you manage the budget for the services you receive under this plan. *(For more information about this option, see Self Determination chapter, pg. 217.)*



*Ask your care manager to connect you to people who are successfully managing the consumer directed services option.*

**Quality of Life Expectations and Outcomes**

FC is more than a program which provides you services. It is also supposed to help you attain as much quality in your life as possible. FC outcomes are to include, but are not limited to: safety; best possible health; self-determination and choice; living the daily routine you wish to; privacy; respect; member independence; maintaining ties to family and friends; continuing involvement in your community; and being employed as you desire.

**Family Care outcomes**

**Negative personal outcomes**

You have a right to not experience the following personal outcomes: disruption of your relationships with your friends or family members; isolation from your community and the activities you wish to be involved in; lack of access to employment; and lack of access to services, treatment or learning opportunities to increase your level of independence. You also have the right to not receive services in places where they are unlikely to be effective; and you have the right not to be placed in locked settings or to be restrained physically or with drugs.

**Right to take risks**

CMO members also have the right to take risks in making decisions about where they want to live and what kinds of service arrangements they wish to make. The CMO should allow continued or additional risk if taking this risk is reasonable in relation to the member's enhanced ability to achieve his/her identified Family Care outcomes.

**Making Complaints about Family Care Services**

Sec. 46.281(h), Wis. Stats.  
HFS 10.53, 10.23(6) and 10.54

RCs and CMOs must have very clear complaint and grievance procedures for helping people who apply for or are receiving FC. These complaints and grievances may be made against the RC, a CMO, or a provider of services. This process must include:

1. Acknowledgment to the person of receipt of a complaint or grievance (**within three days for RC, five days for CMO**) and the projected date of a decision.
2. Provision of the following information to the client upon receipt of a complaint or grievance:
  - statement of client rights in Family Care;
  - information about all levels where a complaint or grievance might be registered;
  - information about organizations that may assist with the complaint or grievance process;
  - an offer to assist the client with submitting a complaint or grievance;
  - an attempt to resolve issues informally, including an explanation of the potential benefits of negotiating an informal resolution before proceeding to more formal grievance processes in terms of timeliness and simplicity of process; and
  - permission for anyone the client chooses to assist the client with the complaint or grievance.

**Enrollment Rights**

Secs. 46.283(f)(g) and  
46.284(4), Wis. Stats.  
HFS 10.23 and 10.45(2),  
Wis. Admin. Code

RCs are to assist new members to enroll in the CMO. All CMOs must enroll any person referred by an RC, regardless of that person's life situation, health, severity of disability, or cost sharing requirements. Enrollment occurs in the order of referral. New CMOs have the right to limit enrollment during their first 24 months of operation to have time to build capacity to serve their service areas.



## Protections Against Involuntary Disenrollment

Sec. 46.286(3)(b), Wis. Stats.  
HFS 10.45 and 10.55(1)(g),  
Wis. Admin. Code

The only circumstances foreseen in which a person may be disenrolled from FC against his/her will are:

1. The member is no longer eligible for FC.
2. The member refuses to pay his/her cost share.
3. The CMO contract with the county or tribe is not renewed.
4. The member has assaulted an employee or a provider.
5. The CMO has documented that it has offered the member “reasonable alternative” services, that the member refuses these services, and as a consequence his/her health is in immediate jeopardy.

**No involuntary disenrollment by a CMO is effective unless the Department of Health and Family Services has approved it.**

Sec. 46.284(4), Wis. Stats.  
HFS 10.45(2)(b)

**RC assistance to members**  
HFS 10.23(2)(l), Wis. Admin. Code

The RC is required to provide all members assistance with either voluntary or involuntary disenrollment. This assistance includes information about rights and grievance procedures; advocacy assistance; and service options for the person if involuntary disenrollment occurs.

## How Family Care can Assist Private Pay Individuals

Sec. 486.284(f), Wis. Stats.  
HFS 10.37

“Private pay” individuals are those people who purchase CMO services with their own funds. These are people who need LTC assistance but do not qualify financially for FC, are FC eligible but not entitled to receive FC immediately, or are entitled to FC but are waiting for CMO enrollment due to county phase-in of FC.

Resource Centers will provide long-term care options counseling to any individual who is elderly or has a disability regardless of income.

These individuals may not enroll in a CMO but may purchase CMO services, including case management, on a fee-for-service basis, at rates normally charged to the public.