

## Nursing &amp; Primary Care

## Main Family Caregiver

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**ABSTRACT**

*Seriously ill people are often unable to oversee their illness or live their lives independently. Nor are they always able to make responsible medical based decisions. Family caregivers can fill this gap. Often one particular family member assumes this role. This person is termed the main family caregiver (MFC). The motivating factors for taking on this demanding voluntary role are complex and variable. Legal designations such as advanced directives or medical power of attorney, where they exist, may, at most, clarify the delegation of authority to the MFC but do not provide guidelines regarding fulfilling their role. Furthermore, this delegation is often informal or de facto rather than official or legal. In addition, a changing situation such as a deterioration of the patient may render a previous formal arrangement no longer relevant. Their task is complex because of the various demands made upon them, which may include technical skills, making crucial decisions and possible ethical conflicts. Moreover, the medical system, with its patient chart-based approach often does not address MFC involvement, even when critical and decisive. As the patient's condition deteriorates, the nature of the MFC relationship with the patient evolves from primarily a family member to primarily a caregiver role. In the course of time, the MFC may find themselves overwhelmed or unable to perform their tasks competently. In short, the medical system frequently fails to acknowledge or take into account the important challenging and helpful role that the MFC plays in patient care. The attending physician, along with the treatment team, should guide and support the MFC in order to optimize their role in supporting their loved one.*

**Keywords**

Family, Care, Nursing.

**Introduction**

“No one is useless in this world who lightens the burdens of another.”

— Charles Dickens.

**Case Presentations**

M is a 96-year-old woman who lives on her own. She is able to walk safely with a walker, her mental faculties are intact, and her hearing is adequate. She takes only a few medications, including for mild diabetes. She sees her family doctor regularly to follow how she is doing in general, and specifically to follow her diabetes.

H is a 74-year-old woman who was diagnosed and aggressively treated for leukemia several years ago. She is medically stable. She lives at home with her husband. She is cognitively intact and

ostensibly independent. However, along with the emotional burden of her condition, she has to deal with the chronic consequences of the disease itself along with the side effects of treatment, which is difficult for her. Consequently, she requires help for many simple home tasks, and is not physically stable enough to be alone for more than a few hours at a time. The tertiary hospital treating her leukaemia is an hour and a half drive away.

P is 85 and resides in a nursing home. He has a plethora of medical problems, including dementia and past stroke. He does recognize his family, but not much more. He is paralyzed on one side and wheelchair bound. He requires help in all the activities of daily living (ADL) such as feeding and transferring. One day he develops a high fever, which has not responded to medication (antipyretics), nor antibiotics and the question of referral to hospital arises.

Above are 3 common case scenarios which many physicians typically would diagnose and treat.

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However, as these cases are presented, they overlook the important point that in none of them do the patients manage independently. Invariably, there is at least one supporting caretaker involved, usually a family member. Although instrumental to their care, the essential involvement of the caregivers is not typically mentioned or addressed.

The first case refers to an elderly individual who for the most part is healthy and independent. However, her daughter attends to most of the IADL (Instrumental activities of daily living) such as home maintenance, medications, and the increasing need for supervision. In addition, she accompanies her mother to the physician's office and is actively involved in the dialogue of care that takes place with the physician.

The second case depicts an overwhelmed individual who has a chronic disease with profound issues, due to both the disease damage itself and treatment side effects. Her husband manages visits with the physician, accompanies her to specialists, and in general deals with the medical bureaucracy. In addition, he provides all the practical support at home.

The final case of S deals with an individual institutionalized with both physical and cognitive problems. While the nursing home team meets his daily needs, he lacks even minimal understanding or ability to make decisions regarding his short or long-term options, such as possible hospital referral. His son provides these services.

I term these people the Main Family Caregiver - the MFC. Often there is one predominant family member - a spouse, son, daughter, or parent - who takes responsibility for the care of a dependent family member.

### **Definition**

*The main family caregiver (MFC) is the involved individual who is responsible for the personal care, nursing, and medical needs, usually of a relative, who cannot function independently.*

### **Detailed Depiction**

In the home setting, the spectrum of situations includes accompanying a person with a debilitating disease or a complex illness, an individual with multiple co-morbidities, and virtually any individual who cannot cope with the burden of their illness without support. In the context of an institution such as a nursing home, even though a professional team provides the personal, nursing and medical care, the MFC role is still relevant and particularly important as the resident's advocate and when critical care and value-based decisions are to be made.

The term MFC is overarching conceptually and is not necessarily limited to a single person. The role may be divided among family members. As an example, S was a 93-year-old nursing home resident with dementia and diabetes. Three adult children were actively involved: a son who had a good grasp of medicine and his father's medical conditions, visited him frequently, and was

in regular contact with the physician; the daughter who was emotionally closest to her father and best able to draw attention to his general turmoil and difficulties, while the second son, the designated power of attorney, was responsible when crucial legal or medical decisions had to be made. Together, they fulfilled the role of MFC.

### **Ubiquitous nature of MFC**

One study has shown that about one quarter of adults are caretakers [1], illustrating that the need for family member caretaking is ubiquitous. Despite their central importance, the physician, using a patient chart-based approach, usually does not address MFC involvement even when it is critical and decisive. Physicians, and often other team members, do not generally receive training in integrating the MFC into the care of their patients and may lack the skills or not find the time to talk to family members in any detail. Concerns about confidentiality, sometimes exaggerated, can exclude the MFC from access to information necessary for understanding the situation.

### **Reasons for taking on the role of MFC**

The motivating factors for taking on this role of MFC are complex and variable. Rather than out of a purely altruistic desire to help the patient, a common driving force for taking on this voluntary task is the stark realization that otherwise there will be no one to fill this vacuum such that the wellbeing of their relative will be compromised. Past problematic relationship, issues between the patient and MFC and acting out of an admirable sense of (family) obligation rather than pure altruism can make the motivation to help more challenging.

### **Demands on the MFC**

The task often is both emotionally demanding and disruptively time consuming. Because problems can occur unpredictably, planning can only help so much. Analogous to properly taking care of a child, it requires an adjustment in personal priorities.

There is no official manual on how to be an effective MFC. Depending on their personalities and life experiences, some of the tasks and responsibilities may be unfamiliar or awkward for the MFC to fulfil.

### **Understanding The Patient's Medical and Nursing Situation**

To play an effective role, it is important that the MFC understand the patient's current medical condition and what likely lies ahead (prognosis). A knowledgeable MFC can better help the patient in interactions with the caretaking team and improve the patient's compliance regarding treatment recommendations.

### **Role of MFC in the Home Setting**

Tasks, which may require MFC involvement:

- **Non-medical issues:** In the home setup, along with more general needs - (instrumental activities of daily living - IADL), there are personal care needs (ADL - activities of daily living). **Nursing needs:** may include basic nursing tasks such as taking blood pressure, sugar measurements and others. Even when

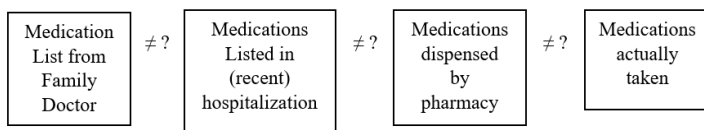
there is a professional home caregiver, typically the MFC will supervise and at times stand in for them.

- **Medical needs:**

**Medication management**

This category includes obtaining prescriptions from the doctor and medications from the pharmacy. In some cases, medications require special authorization, which involves paperwork and knowhow.

The ultimate task is to ensure that the medications are administered as indicated by the physician. When people are on multiple medications with difficult to pronounce and remember names, often with similar sounding different generic substitutes, this may not be a straightforward task for non-professionals. Common errors include forgetting to give a medication, inadvertently giving the same medication twice because of different generic names, getting the pills confused, and failure to remove out-of-date or inappropriately stored drugs [2]. In addition, there may be a mismatch between the medications listed on a recent hospital discharge summary, the family physician’s list, the medications dispensed by the pharmacy, and the medication that the patient actually takes. One study found medical non-adherence to be 38% [3].



Incorrect use of medication can lead to serious problems, including preventable hospitalizations and even death in diseases such as heart failure [4,5]. Knowing the purpose, the correct dosage and application of each of the prescribed medications enables the MFC to optimize pharmacological compliance and minimize iatrogenic (error in treatment) complications.

**Logistical medical**

Examples include assistance in preparation for medical tests, arranging and accompaniment to appointments and transportation.

**Assessing and dealing with acute problems**

The assessment and handling of sudden complaints or deterioration in the patient’s medical condition can be daunting for the MFC who may lack the basic knowledge for assessing the severity and treatment options of a sudden acute problem such as fever, irregular sugar levels, shortness of breath or new onset or worsening pain. It is not always straightforward for anyone, let alone a nonprofessional, to ascertain *how abnormal a medical problem must be* to justify action such as contacting the physician or going to the ER.

**Strategic decision making**

Another task is dealing with strategic medical concerns. While some decisions are purely medical or dictated by protocol, other decisions may depend on personal preferences or values rather than standard medical considerations. Value preferences are particularly relevant at decision junctures where there is no obvious good solution.

Should a patient with a host of medical problems go for elective surgery and run the risk of complications? What about continuing with chemotherapy when it probably is no longer effective, but there is no other treatment option? When hospital referral is being considered for cases where potential benefit is not clear-cut, input should be elicited from the patient and family. Past hospitalization experience, especially for a similar problem may significantly influence preferences and the patient themselves may not be in a state of mind to make a responsible decision. Furthermore, since hospitalization almost invariably requires intense family involvement, from admittance to in-hospital and post-hospital care, when possible, the MFC’s opinion should be elicited before the physician reaches a final decision about hospital referral.

MFC involvement in the decision-making process can mitigate the decision burden on the patient and perhaps lead to a more fitting tailor-made solution in these sort of excruciating dilemmas.

MFC involvement can also be an indispensable asset when dealing with end-of-life situations. When advanced directives are not in place or not relevant, the role of the MFC becomes paramount. While the physician can take the lead in pursuing symptom control, the MFC can help in guiding the treatment team how much to medicalize the dying process. When setting location options are available, together with the patient, the MFC can also help in deciding what is their preferred set up - home versus hospital or other institution, each with its own pros and cons.

The MFC involvement in optimizing the decision-making process can be fraught with difficulties. What should the MFC’s stance be based on? I believe that there are three “voices” which must be heard:

**The patient’s known view:** Patients frequently have preferences, even those whose cognitive faculties are compromised. A case in point was a nursing home resident P. suffering from advanced dementia whose communication skills were limited. When he was told that he might be hospitalized because of a new problem, he abruptly became focused. His response was categorically negative. As poor as his cognition was, in his case, he was sufficiently alert and motivated to try to avoid re-experiencing what might turn out to be another traumatic hospital stay.

**Involving the patient by proxy:** When patients are unable to provide useful input and advanced directive are not in place, one can utilize the relationship between the MFC and the patient to bring into the discussion what is known about the resident’s view. Often these topics have been discussed in the past and opinions expressed even if not written down.

**The MFC’s view:** Just as the treatment team can at times “know what is best for the patient”, so too, the MFC may have views which differ from those of the patient.

**Other family member’s views:** There may be situations where the various involved family members have different views.

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## Family Member Coordination

In theory, one might like to be able to directly involve all significant family members in following the course of disease progression but for practical reasons, this is rare. The MFC can play a contributory role in updating the other family members. When decisions need to be taken, the MFC based approach is still workable, even if family members have other views, so long as the MFC accurately conveys such divergent views to the physician. However, some pivotal situations justify actively communicating with more than one family member.

It is the physician's ultimate responsibility to decide what to do. In pursuing that goal in complex situations with value-based considerations, the physician should clarify these voices and along with the medical exigencies, and the physician's own considerations, decide how much weight, if any, to give to each of them. Ideally, the patient's preference supported by the family and physician should be pursued whenever applicable. However, if a consensus cannot be reached and the upcoming decision is crucial, a family conference, perhaps with patient presence, may be indicated.

### Tasks of the MFC in the context of institutionalized care (nursing home)

For the institutionalized, even when everyday tasks are handled by the nursing home, there is still a need for an involved family member, especially when dealing with a resident whose cognitive status is compromised. The important role of resident advocacy became obvious in its absence at the beginning of the COVID pandemic, when in many nursing homes, patient care had been mismanaged before and during the pandemic. The pandemic in those nursing homes exposed the mismanagement (when it occurred) and the inadequacies, which led to lives, lost unnecessarily [6]. Had the families been able to play a more involved advocacy role, perhaps some of the shortcomings could have been rectified. One should clarify that not all nursing home outbreaks were the consequence of sub-optimal care. Studies showed for example, that the higher the incidence of COVID in surrounding communities, the more likelihood there was of a nursing home outbreak even when precautions were taken and the nursing home functioned well [7].

### Two important complementary roles for the MFC

**Acting as the patient's advocate:** The MFC can stand up for the patient's rights. A physician may forget to write a prescription or order a test. Sometimes, people working within the medical system can be harsh and insensitive. The medical system itself can present problems, for example in accessing special authorization for a medication or test. In such instances, the MFC can play an interventionist and assertive role in helping maintain appropriate quality of care.

**Acting as a liaison between the "system" and the patient to elicit patient compliance:** Patients, especially the very ill, tend to be preoccupied exclusively with their own circumstances and consequently may have a distorted impression of what can and cannot be done for them. Because of this or because of personality

quirks, they may be uncooperative or make unrealistic demands on the system and thus risk alienating those very caregivers who want to help. In such situations, the MFC may be more successful at improving on-going patient cooperation and compliance.

Some or all these above-described tasks may be unduly challenging for the MFC.

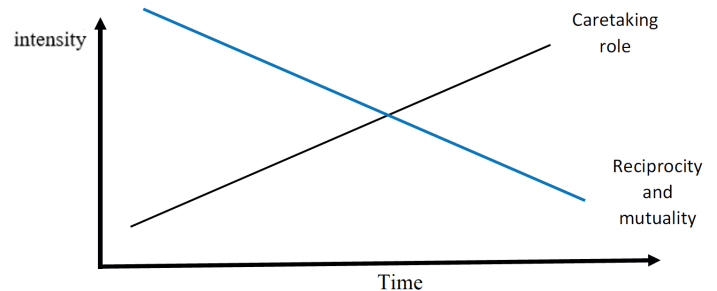
### Further challenges interfering with the efficacy of the MFC

- Unwillingness of the physician and treatment team to actively work with the MFC.
- Lack of competence with regards the skills required e.g. changing a bandage or calibrating an insulin pen.
- The MFC may not totally understand the patient's illness, accurately appreciate its severity, or have unrealistic goals of treatment.
- The MFC may well have their own health problems or other issues, which require attention and conflict with provision of support. Taking care of a relative may affect and disrupt their other life routines.
- The emotional stress and time demand of caring for a close loved one may be overwhelming to the point of harming their own function and emotional equanimity.

### The role transition from a primarily voluntary interactive relationship to one in which the MFC becomes primarily a caregiver

When an individual's personal, physical, or cognitive functions deteriorate, they will become progressively more dependent on outside support and cooperation to manage their lives and illness. This results in an increasing need for the involvement of a MFC, which may start as a mutually acceptable, interdependent relationship and develop into one of increasing dependence on the MFC. Recognising this transition will make it emotionally easier for the MFC to accept that the reciprocity that once existed is receding.

### Characteristic of relationship between patient and MFC as a function of disease progression



### Issues with the Patient – MFC and family relationships

- Some MFCs are better able to empathize and see the situation from the patient's perspective while some are less able.
- The patient may not necessarily cooperate with the MFC nor be appreciative of what is done for them.
- If the pre-illness relationship between the patient and MFC has been problematic, the past grievances may now interfere with



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- ongoing accompaniment.
- There may be lack of commitment to the primary well-being of the patient due to financial or other reasons. While my experience has been that most MFCs act in the interest of the patient, this is not universally the case. As an example, the MFC may reject a recommended intervention because it will cost money and deplete possible inheritance.
  - Other family members may be critical of the MFC but unwilling themselves to play a more active role.

### **Growth potential**

While dealing with disease progression can seem like an endless nightmare for both the patient and the MFC, there are potential areas of light, one of which can be growth in the relationship between them. Satisfaction can paradoxically be derived alongside a worsening overall medical state due to a joint role in promoting patient welfare. Often a deepening relationship between the patient and the MFC provides the patient with comfort and strength and the MFC with a sense of personal satisfaction and pride. I have frequently witnessed and been inspired by the closeness established between a son or daughter and parent which did not exist before or might even have been absent during their childhood when the roles were reversed.

### **Displaced Anger of patient [8]**

Sam was a 75-year-old widower nursing home resident. Neither of his two sons took on the role of family carer but one of his daughters-in-law's, Rachel, filled this role with great devotion and regularity. Yet, she was the target of ongoing unwarranted complaints and criticism from her father-in-law, who in contrast, never complained about his sons' neglect.

*This perplexing phenomenon of unjustified criticism directed at the MFC is not uncommon.* It is a situation in which the most responsible and loyal family member endures the brunt of the patient's anger and frustrations. This exemplifies the concept of "displaced anger": the unconscious venting of negative emotions at a safe target rather than at the actual source.

It is fair to presume that most people with incurable, progressing or debilitating illnesses harbour anger, resentment and hostility be it due to a delay in diagnosis, a complication along the way, delivery of sub-optimal treatment, loss of independence, financial status and more. If this anger is severe enough, they unconsciously seek an outlet to vent their emotions.

This unconscious hostility often is not directed at the physician nor other care workers for fear of retribution. If directed at themselves, it may well manifest itself by poor compliance, poor cooperation or even onset of depression. A "better" unconscious alternative is to direct the anger at a "safe target", the loyal, conscientious caregiver who will continue to provide care regardless of the patient's hostility and criticism. In the above case, Sam, who was likely angry at becoming more dependent on others and having been abandoned by his two sons, vented his anger unconsciously on Rachel whom he knew would continue to attend to his needs. In

Freudian terms, the ego seeks out a safe way to reconcile between the id and superego pressures [9].

There may be legitimate reasons for the patient to express anger at the MFC, in which case the complaints should be addressed. However, when the intensity of criticism seems to be out of proportion to the nature of the complaint, it is recommended to consider displaced anger as a possible explanation.

Since this is an *unconscious* process, bringing it to the attention of the *patient* will likely fail and incur bewilderment or even anger on their part. It is best to simply explain the process to the *MFC*. A persuasive explanation can usually mitigate the MFC's feelings of self-guilt (at themselves) or anger at the patient which they may harbor, providing them with the understanding to continue to fulfil their sometimes unpleasant but important MFC role.

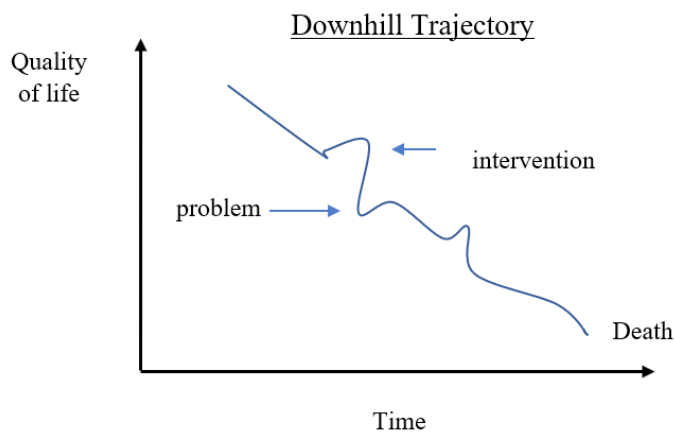
### **Navigating the degree of involvement in the decision-making process**

The degree of involvement of the family in critical decisions lies on a continuum from wanting to dictate to the physician what should be done, to leaving everything up to the physician. Most people, however, position themselves somewhere in the middle, where they mostly want to understand what is going on, with the occasional option of expressing a preference. They expect the physician to make the ultimate decisions. The physician can often ascertain precisely what degree of involvement the MFC is comfortable with and try to match their approach. Some may want to be regularly informed about minor changes, while others prefer only to be told about the more critical developments. I have found generally that people primarily want to accompany the process rather than decide it. At each important juncture, they want to understand in layman's terms the rationale behind what the physician intends to do.

This involvement can minimize the family's sense of outsider helplessness and improve patient compliance. Many options, even preferred ones, have a downside to them such as medication side effects. Ultimately, if the MFC can be persuaded that despite its disadvantages, the recommended option is better than the alternatives, they will be more cooperative, and may assist in eliciting patient compliance.

### **Long term benefits of MFC involvement in the decision-making process**

- Coming to terms with the concept of the "least bad" solution: The above termed "preferred" solution, though, may not initially meet the MFC's expectations. Part of the decision-making process requires of the MFC to understand rationally and reconcile emotionally the fact that whatever option is selected will often be a compromise trade-off and only at best partially beneficial. That is typically the nature of a downhill trajectory.
- Having been actively involved in accompanying the patient step by step on their downhill course, it will be easier for them to come to terms with the ultimate death of the patient.



### Supporting the main family caregiver

**Interventions to optimize MFC involvement:** This is presuming that the MFC has been designated legally or at least the patient has consented to the MFC's active involvement.

1. **Acknowledge and verbally validate what they do:** Since medical systems typically do not have a place for MFC involvement, it helps for the physician to verbally acknowledge their important role.
2. **Provide the MFC with appropriate information:** Providing enough ongoing information about the patient's condition and prognosis enables family members to play an active role in overseeing treatment and assist in decision-making.
3. **Provide them with positive feedback:** Try to put the spotlight on effective MFC interventions. An example might be MFC success in obtaining a special medication, which the physician recommended, and which has led to an improvement in the patient's condition. It is worthwhile acknowledging their contribution. They deserve the recognition.
4. **Synchronize expectations:** Coordinating realistic expectations with the MFC (and presumably the family) can facilitate the work of the treatment team. Especially in situations in which the patient is unrealistic about their future, unable to understand their situation or not yet emotionally prepared to contend with a poor prognosis, involving family members who have a realistic understanding of the situation can be helpful.

### 5. Clarify the ground rules:

#### Questions to be considered

- i. Under what conditions (if any), can the MFC of a community-based patient initiate physician contact?
- ii. In a patient encounter, may the MFC be present and if so, are they permitted to initiate questions and take part in the deliberations?
- iii. When dealing with an institutionalized patient, under what circumstances can the MFC contact the physician? Under what circumstances will the physician contact them? In addition to

being the bearer of bad news, occasionally it is appropriate for the physician to report good news such as an encouraging improvement or even an unexpected normal test result.

6. **Navigate the degree of involvement of the MFC to the satisfaction of both sides:** Once a coordinated dialogue has developed, communication is usually straightforward, and the MFC may even be viewed as a sort of extended team member. Effective communication with the MFC can be a channel of positive feedback from the MFC to the physician and treatment team and vice versa.

### 7. MFC wellbeing

In addition, if the MFC themselves has an issue such as a health problem which they have shared with you, periodically ask for an update. Periodically ask how they are doing? Then listen. Their own journey of learning and adapting to their role as an MFC and their evolving relationship both with the patient and the treatment team is complex. It may be both emotionally challenging and at the same time satisfying. Alternatively, the MFC may simply be overwhelmed by their sense of responsibility for the patient's troublesome medical developments. An acknowledgment by the physician of the important role that they are playing will be a morale booster, enabling them to better cope.

Personally, I view the main family caregivers as life's quiet heroes who deserve the physician and team members' expressed respect and appreciation. Furthermore, there is no doubt in my mind that having the MFC on board eases provision of patient care.

### Summary

Whether acknowledged and coordinated with the medical system or not, involvement of a MFC is commonplace, extensive, and significant. The physician and treatment team can usually facilitate the MFC's participation with minimal effort. To optimize MFC involvement mostly requires a physician attitudinal change. I believe that coordination with the MFC, initiated by the physician and / or another member of the treatment team, can improve patient care and ease the tasks of care for both the MFC and the treatment team.

### On a personal note

From my perspective as a physician, I have found that my involvement with the main family caregiver though it is time consuming, has both deepened my understanding of the patients I have treated and has been a particular source of satisfaction, especially in cases where the patient's participation capacity in their own care is compromised.

Dr. Jim Shalom

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