the People's Doctor

A MEDICAL NEWSLETTER FOR CONSUMERS by Robert S. Mendelsohn, MD

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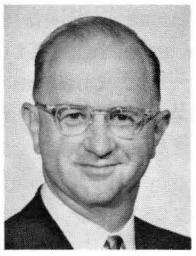
Coping with Hospitals



I often have remarked that one should treat a hospital the way one does a war--stay out of it if you can, but if you must get into it, get out as fast as possible. I was pleased, then, to see a New England Journal of Medicine article on a hospital-stay study done at Duke University Medical Center. Sixty-seven patients who had suffered acute myocardial infarctions, but had no serious complications during the first four days in the hospital, were considered for discharge after one week. Half of them were sent home after a week, while the rest stayed from nine to 13 days. Neither group had suffered any serious complications three weeks after being discharged, and there were no deaths and no differences in functional status at six months. The study concludes that such patients "can be spared the economic costs and psychologic stress of prolonged hospitalization."

This issue of my Newsletter concerns itself with many aspects of hospitalization, from the birth of a baby to the death of an aged relative. For most patients, hospitals are a strange land in which the rules of normal behavior are suspended and natural rights are taken away. I hope some of the following questions and answers will provide you with a roadmap that will help you navigate, as swiftly as possible, through that often-frightening world of the hospital.

Q A

A patient's rights

What are my rights when I enter a hospital?--S.M.

Your rights in a hospital are the same human rights you have in the outside world. You have the right to ask questions, to complain, and to refuse treatment. The difference is that it can be very difficult to exercise those rights in a large, often impersonal institution, especially when you're in a weakened condition. That's why I always urge that another family member be present as much as possible when a person is hospitalized --it's like having a personal ombudsman.

It may help you to know that the American Hospital Association has issued a "Patient's Bill of Rights" which it has supplied to its member hospitals. Here's some of what that "bill of rights" says the hospital owes you:

1. Complete, current information on your diagnosis, treatment, and prognosis, delivered in understandable language.
2. The right to refuse treatment and to be informed of the medical consequences of such action.
3. The confidentiality of all records and communications which deal with your care.

4. "Considerate and respectful" care.
5. The right to be consulted if the hospital wants you to take experimental drugs or participate in experimental treatments.

Above all, don't allow yourself to be intimidated. You are entitled to the same personal dignity in a hospital that you have outside its walls.

Q

My mother is critically ill and hospitalized in an intensive care unit. I'm allowed to visit her for only 10 minutes once every two hours. The nurse tells me that it's too much of a strain for my mother to see me for longer periods of time, but I feel that she needs me to be with her. What is your advice?--T.D.

A

Visiting in an intensive care unit

Tell the nurse you think your visits are soothing to your mother and not a "strain" on her. After all, who is in a better position to evaluate your mother's mental state--her daughter or a stranger?

If the nurse then claims that in her "professional judgment," you are wrong, challenge her to produce evidence. She may then strategically retreat to a new position, namely that "these are hospital rules." If so, ask her for a copy of those rules in writing. If the nurse can't produce them, it won't be the first case of "invented" hospital regulations.

Such a challenge to produce written rules is best given as you are standing at your mother's bedside at the end of the 10-minute visit. Since you are already there, it is the nurse who must take action if she is to remove you from your mother's side.

The nurse may then move to yet another strategic position--that of calling the intern or resident. Your countermove, of course, is to ask the physician the same questions you've already asked the nurse, namely, "How do you know that my presence here causes a strain on my mother? How do you know that the presence of hospital professionals is automatically good and the presence of family members is automatically bad for the patient?"

If all this sounds like a chess game, that's just what it is. You must plan each move carefully, and you must decide how much you're willing to risk to stay in the game until the finish. (A policemen CAN be called to evict you physically.)

There must be a hospital somewhere whose personnel understand that visiting is a right, not a privilege divinely bestowed by hospital authorities. I would like to hear from anyone who knows a hospital that either permits close relatives to visit their critically ill kinfolk without hospital-imposed restraints or at least allows them to participate in the decision of what constitutes reasonable visiting times.

Q

Complaints about ICU visitors

We are two Intensive Coronary Care Unit nurses who would like to thank you for the damage you've done and for making our job harder.

Before you hand out advice to people about staying with critically ill patients, you might ask a few questions. We often let a family member stay constantly with a critical patient if we feel it is for the patient's well-being, but we also have to put up with families of 12 children who all want to stay, who turn our unit into Grand Central Station, or who think that we should also stay with them constantly. Or there's the family that comes in drunk, maybe trying to get rid of guilt feelings.

As with anything, the few bad ones ruin it for the good ones. Rules are not made for the reasonable, understanding and concerned, but for the unreasonable, demanding and often obnoxious visitor, of whom, believe it or not, we have our share.

That you actually feel an apprehensive, often overwrought relative is the best qualified to evaluate the patient's mental state is beyond us. It certainly shows that you spend much more time writing articles than visiting ICCU's.

We certainly hope for the sake of our patients that you'll get the facts straight and print some kind of retraction. The daughter who wrote you about her mother is probably a very nice person who read the posted hours and took it as gospel, because who has time to keep track of every visitor and how long they stay when you're working in an ICCU?--Two Irate Nurses

More on ICU visiting

A

I print your letter for those readers who may never have heard the time-worn, elitist, anti-visitor arguments often propounded by doctors and nurses.

This certainly isn't the first time I've heard visitors referred to as "apprehensive" (who wouldn't be?), "unreasonable," "demanding," "obnoxious" and "guilty," but it is the first time I've been accused of seldom having been inside an intensive coronary care unit.

Not only did I visit a patient last week in my own hospital's ICCU, but I also was in charge of what may have been one of the first intensive-care units when I ran the polio ward at Michael Reese Hospital in Chicago in the early 1950's. At that time we had open visiting for patients in all stages of polio--acute, chronic, spinal and bulbar.

Unlike you irate ladies, we felt that visiting--whether by parents, other relatives, school classmates, neighbors or friends--was not a PRIVILEGE, to be meted out by "gatekeeper" nurses but a RIGHT of every patient. Visiting is not only a right, but also a crucial factor in aiding recovery. And that's what hospitalization is supposed to be all about, isn't it?

Q

You have asked if any of your readers could tell you about hospitals in which critically ill patients were not deprived of visits from their families. I know of one such hospital in Peoria, Illinois.

When my mother was in the Intensive Care Unit there, the hospital rule was that the family could see the patient for 15 minutes every hour. But the ICU staff let the family use its own judgment as to how much time to spend at the patient's bedside. Since we understood that mother needed sleep, we didn't stay at her side constantly, but we knew that whenever she asked for us, the nurses would come and get us.

After Mom was moved to her own hospital room, I was allowed to stay with her day and night until we took her home three weeks later (she wanted to die at home). Before we left, the hospital nurses taught me how to care for Mom properly, and even showed me how to give her shots for pain.

I will always be grateful to this hospital and its personnel for making my mother's last weeks and months as easy on everyone as possible.--Mrs.C.L.

Good hospital visiting procedures

A

Your letter illustrates beautifully how good, caring hospital personnel can work around seemingly inflexible hospital rules. The difference between a satisfactory and unsatisfactory hospital stay often boils down to how well hospital employees succeed in bending the rules.

Some other hospitals that readers have written me about include:

Georgetown University Hospital, Washington, D.C. ("The doctors felt my daughter knew her husband's emotional needs better than they did.")

"A large well-known hospital" in Chicago ("I am reluctant to tell you the hospital's name for fear that those who bent the rules and regulations might somehow come under fire from those higher up.")

Our Lady of Victory Hospital, Lackawanna, N.Y. ("The hospital personnel are all very understanding and in some ways appreciate our being there with mother. It is a comfort to her as well as ourselves that we can be there at all times.")

St. Luke's Hospital, Milwaukee, Wis. ("I have never been in a hospital where everyone was so well treated; the nurses and staff are terrific.")

Children's Hospital, Buffalo, N.Y. ("I was allowed to be with my wife 24 hours a day; a lot of people cared.")

Cottage Hospital, Galesburg, Ill. ("Although visiting hours are supposed to be only five minutes each hour, no limits ever were placed on me.")

Presbyterian-St. Luke's Hospital in Chicago ("I cannot say enough about the tremendous care my husband received. I spent hours at his bedside, and I received the same 'tender, loving care' as did all members of our family.")

Thank you for sharing some of your heartwarming experiences with me.

A *Visiting the sick*

One of my readers sent me a clipping in which an advice columnist told people not to visit sick friends in the hospital, conseling them to send a card or flowers instead.

I am sure there are times, such as immediately after surgery, when visiting is unwise. But it seems ridiculous to allow these few exceptions to eclipse the basic human need for companionship in time of crisis.

From a medical viewpoint, visitors certainly can help alleviate feelings of isolation, abandonment and alienation that are inherent whenever a person is removed from his home and family and placed in an institution such as a hospital. Visits, particularly those of family members and close friends, protect the patient against the ever-growing danger of errors in hospital procedure, such as dispensing the wrong medication or incorrectly identifying a patient. Furthermore, in these days of inadequate hospital staffing, the visitor often represents an invaluable pair of hands, a fact that can be attested to by anyone who has ever pressed a button for a bedpan that never came.

I advise all my hospitalized patients to keep someone with them all the time, particularly when the patients are young children or the elderly. I have previously stated that a hospital is like a war; I would now add that, as in a war, you should not enter the hospital without allies who can help ensure that you receive the greatest possible benefits with minimal risks.

Finally, every religious tradition I know of, my own included, teaches the general rule of visiting the sick. Cards and flowers are certainly nice, but they are hardly a replacement for the face-to-face contact of one caring human being with another.

Q

Last year I gave birth to a son. I had him by the Lamaze method of prepared, natural childbirth, and it was really quite beautiful. Only one thing was missing--my husband.

With the Lamaze method, the father is supposed to have a part in the birth of his child. He is there for moral support, to coach the woman in breathing and pushing and to experience this exciting event. My doctor didn't agree; he said my husband might get sick or faint.

While he is a fine obstetrician in all other aspects, I think my doctor is afraid to be the first in our city to include the father in the experience of childbirth because he's afraid of being ridiculed by his fellow doctors.

For centuries, fathers have been treated as second-class citizens who carry deadly germs and are too weak to handle the sight of birth. The time has come to change this; fathers have a right to be present at the birth of their children.

I am hoping you can say something that will make doctors realize how great an injustice this is. Other cities readily accept fathers in the delivery room, but my city hasn't accepted it at all.--Labored in Pensacola

Husband in hospital delivery room

Your letter reminds me of an experience one of my medical students had a few years ago when his pregnant wife asked her obstetrician to let her husband be present during the delivery of their baby. The doctor replied that he felt the delivery of a baby was far too personal an event for the father to be present. The mother-to-be replied that if it were all that personal, she wasn't sure whether the obstetrician should be there! (Their subsequent children have been delivered at home.)

It seems to me that more fathers than ever are being "allowed" in delivery rooms. Maybe your doctor will decide to be the Pioneer of Pensacola, especially since ground has already been broken in so many other places.

After reading the letter in your column from Labored in Pensacola, I feel it necessary to refute her sweeping and obviously unresearched generalization about all Pensacola obstetricians refusing to allow fathers in the delivery room.

Four obstetricians of whom I am aware, including the doctor who delivered my own little girl 18 months ago, welcome fathers in the delivery room if they are willing to attend a three- to four-hour prenatal course prior to birth.

I cannot state that ALL the obstetricians here allow this, or that even the majority do (although this may be the case), but there may be pregnant women contemplating a move to Pensacola who will suffer unnecessary concern because Labored says ". . . my city hasn't accepted it at all."

Please print this letter and raise Pensacola from the dark ages to which Labored erroneously relegated it.--M.B.B.

More on fathers in delivery room

Dear M.B.B. (and all the others from Pensacola who wrote me that their husbands accompanied them in the delivery room): I must admit I felt a certain degree of surprise at the original letter from Labored in Pensacola, and I am glad to set the record straight. There has been a remarkable change nationwide on the issue of the father's presence in the delivery room. Many claim this recent change has resulted from enlightened attitudes, while cynics point out that the surplus of beds in many hospital obstetrical units has contributed to this relaxation of rigid rules.

Whatever the reason, restrictions are being relaxed to the point where husbands are now asking (and in some cases, are allowed) to be present during Caesarean sections.

If the present combination of enlightened attitudes and hospital economics continues, it may not be long before we see parents, in-laws, aunts, uncles, friends and even the family cat present at the delivery.

My doctor says that my 3-year-old has to stay in the hospital for seven days after hernia surgery. Will it harm him if I take him home earlier? Should I stay in the hospital with him?--D.D.

Children in hospitals

To determine how long your child should stay, ask your doctor what will be done in the hospital that can't just as well be done at home. Some hospitals even do such surgery for children on an outpatient basis.

Since a child may feel abandoned if left alone in a hospital, be sure that you can stay with him during the days and nights. If you or a family member is constantly present, you will also be able to check his medication,

and you will know whether he is taking tests that are properly ordered for him.

If the hospital you're planning to use will not allow you to stay, ask your doctor to recommend another hospital.

Q I'm going to have a baby next month, and I've heard so much about the dangers of nursery cross-infection that I want to go home right after I have the baby. Will that be possible?--A.M.

A *Leaving hospital after baby's birth*

You've certainly heard right. As a matter of fact, by the time you've decided to go home, it's probably already too late in terms of your baby's possible exposure to infection. The baby will already have been exposed to a large variety of germs, ranging from those on the doctor's stethoscope to those from sick people carried through the hospital's air ducts. You certainly should attempt to get out as fast as you can, but hospital authorities, including your physician, may object. Remember that a hospital is not a jail, and you are always free to walk out. It is not necessary to sign any release forms.

The average maternity stay in a hospital used to be one to two weeks. Now it's four days. In Chicago, the Prentice Women's Hospital and Maternity Center of Northwestern University Hospital will release some new mothers within 24 hours of delivery, if they so desire. Perhaps your local hospital has a similar policy.

Q I recently read that many hospitals are creating family maternity programs where fathers can stay with mothers during delivery and their children can visit afterwards. Isn't this the kind of change you've been advocating? How can we get more hospitals to do the same thing?--J.McK.

A *Hospitals and "family maternity programs"*

I can't blame you for assuming I would be in favor a "family centered" maternity programs in hospitals. After all, who can argue against humanizing some of the present inhuman hospital care? Yet I regret that the situation is not as simple as it seems. While I'm CONCERNED about the psychological implications of isolation which the hospitalized mother must contend with when she is separated from her husband and other close relatives, I'm ALARMED at the potentially life-threatening and disability-producing implications of many present-day hospital obstetric practices.

I refer specifically to the outrageously high number of Caesarean sections performed, as well as the general overuse of analgesic and anesthetic agents that so easily find their way through the placenta and into the infant's vulnerable brain cells. To address oneself solely to the psychological issues of separation while uncritically retaining stirrups, routine elective induction of labor, episiotomy, monitoring, epidurals, Demerol, intravenous fluids, multiple vaginal examinations, and forceps amounts to just so much window dressing. We need to do far more than just slap a coat of bright paint over the crumbling facade of modern-day hospital-based obstetric procedures.

Q When I was recently hospitalized, my first roommate died. The second was quite ill and required supervision by doctors and nurses who constantly trooped through the room. I got very little rest, and my visitors had to

whisper so as not to disturb the other patient. I know it's supposed to be cheaper for the hospital to put two people in a room, but couldn't they save the same amount of money by making all the rooms smaller but keeping them private?--D.P.

Why two patients to a room?

A Hospitals fill up space the way restaurants fill up tables; everyone gets put next to each other even though they could just as well be spread out.

The semi-private room arrangement has always baffled me. In an institution supposedly devoted to healing the sick, why is a patient bedded down next to someone whose physical condition is unknown to him? What kind of germs is that patient in the next bed carrying? What kinds of communicable diseases are his visitors harboring?

Furthermore, what about the patient's right to privacy? How much confidentiality can there be when your case is discussed, however discreetly, in front of another person? How open can you be with your doctor if all that stands between you and the next patient's visitors is a flimsy drape?

Most of us are unwilling to share our bedroom at home with a stranger, even when we're healthy. I cannot for the life of me see why two sick strangers should be exposed to each other's infections and anxieties.

Medical News

The federal government has issued the third cancer warning in history (the first two involved cigarets and asbestos) by citing clear evidence that daughters of mothers who took the hormone DES, the mothers themselves, and their sons may develop cancer or other genital or perhaps urinary tract abnormalities.

Health, Education and Welfare Secretary Joseph A. Califano, Jr. has asked all doctors to check their records and warn such patients and their offspring. He suggests that patients not be charged for this service.

DES was widely used in the 1940's and 1950's to prevent miscarriage. The drug is still being used to treat hormone deficiencies, menopausal problems, advanced breast and prostate cancer, as the "morning after" contraceptive, and to suppress milk production in new mothers who don't breastfeed. The FDA is expected to rule out the last use soon. (Washington Post, September 7, 1978).

Editor's note: Not soon enough for all those mothers who were reassured how painless and safe those dry-up pills were.

Your questions about the medical problems that trouble you most will be answered by Dr. Mendelsohn. Please send your questions to: The People's Doctor, 664 N. Michigan Ave., Suite 720, Chicago, Ill. 60611.

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Another View

by Marian Tompson
President, La Leche League International

It's funny how we can accept things even when they don't make sense to us, the hospital rule prohibiting children from visiting sick patients being a case in point. I always took it for granted that this was an edict enforced by the health department to protect the sick from the particular germs harbored by youngsters under 14 or 16 years of age. At the same time, I knew from experience that this enforced separation of family members only adds to the stress experienced when one of them is ill or injured. Besides it's hard to get well when you are worrying about those you left at home and when you are isolated from the people you care most about.

So I really got excited when I learned that American International Hospital in Zion, Illinois, allows children of any age to visit sick family members. I immediately got in touch with Administrator Robert Helms to learn how American International had pulled off this coup.

Mr. Helms told me that several years ago the hospital's Board of Directors decided they would like to allow children to visit. Upon investigating the rationale behind the old ruling and discovering that it had nothing to do with any kind of state or county health regulations, it was determined that this was simply a matter to be decided upon by each individual hospital. The proposal was brought before the doctors on American International's staff and, with their approval, the new policy was put into effect.

According to Robert Helms, when it comes to making changes in hospital regulations or even getting around them, it is the doctors who hold the power. Hospitals are their workshops, and since they sit on the committees that dictate hospital policy, you can expect hospital rules to pretty much reflect the doctors' philosophy towards patient care. And this is only right, for the doctor has the ultimate responsibility for his patients' welfare.

As a patient, you are most likely to obtain the kind of hospital care you need if you have a doctor who agrees with you about the importance of those needs. So, even if the hospital doesn't provide a particular kind of care (such as allowing a parent to stay overnight with a sick child) your doctor should feel strongly enough to fight for your rights. And nine out of ten times, the administrator will give in. But on the other hand, if your doctor doesn't share your concern he will most likely tell you to handle your own confrontation. You are then usually in a no-win position, because the administrator, recognizing your doctor's lack of support, will more than likely turn you down.

It's true that a growing number of hospitals are hiring "patient advocates" but too often they are little more than public relations persons who explain to the patient why the hospital (which pays the patient advocate's salary) functions in a particular manner.

So I'm convinced that your most effective advocate is still your doctor. Therefore, choose your physician carefully, finding one whose philosophy toward sickness and health matches your own is well worth the effort. For in fighting the battle for good hospital care, as with most of life's other challenges, it's <u>who</u> you know as well as <u>what</u> you know that makes all the difference.

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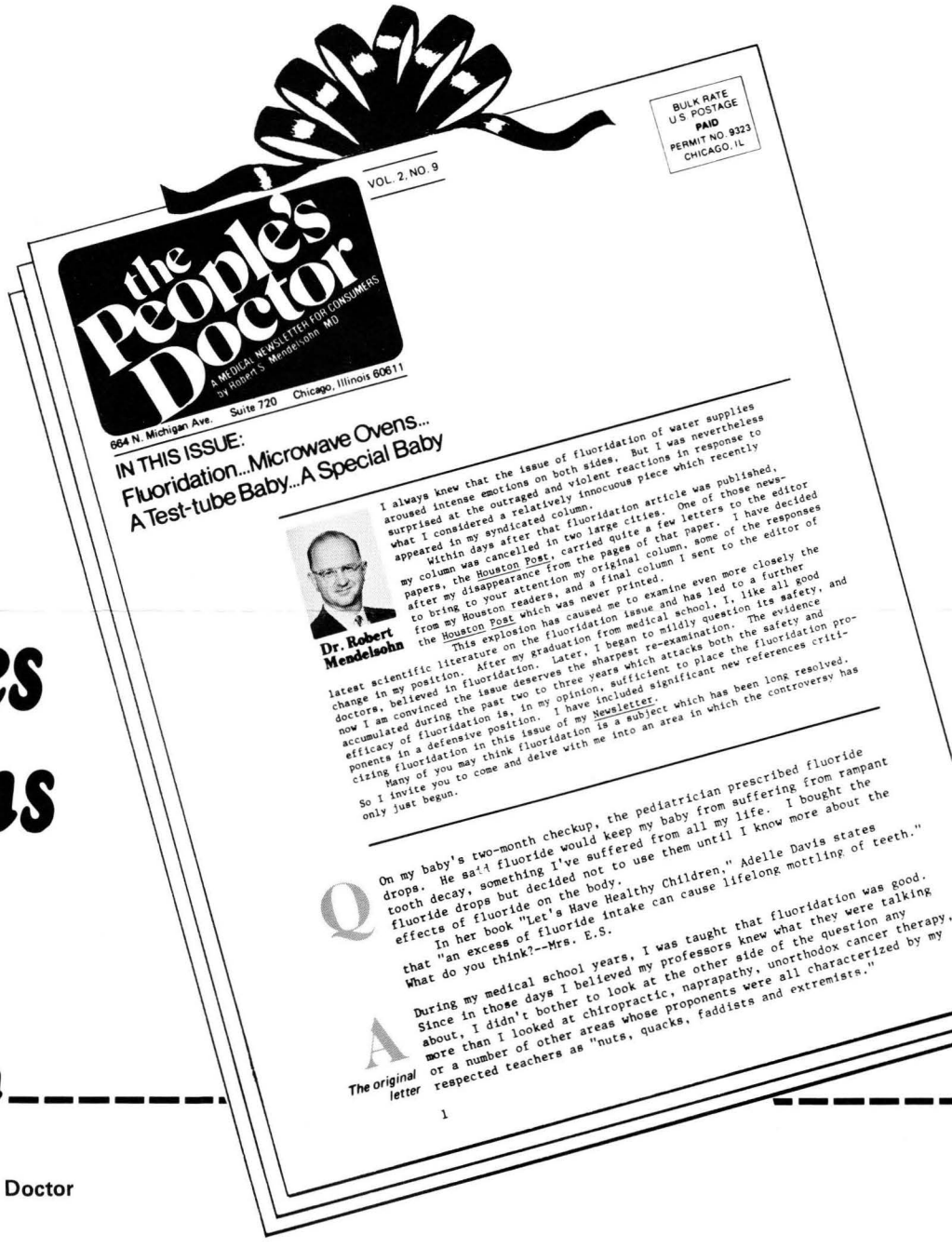

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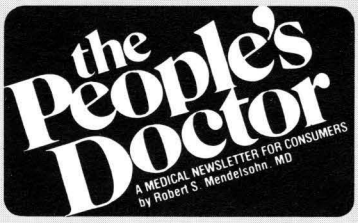

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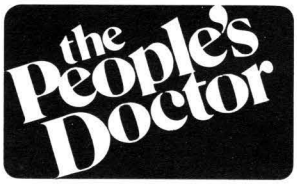

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