

Correspondence – Cancer Care, Inc.

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cancer CARE, inc.



of the National
Cancer Foundation

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The Rev. Barry Goodyear Wood, M.D.

July 31, 1974

Mr. Jimmy Carter,
1974 Campaign Chairman
Democratic National Committee
P.O. Box 1524
Atlanta, Georgia 30301

Dear Mr. Carter,

Since Miss Buckley is out-of-town at the moment attending to important agency business, I am sending you some additional information about our principle concerns on which you may wish to be informed.

May I also point out that the name of our organization is Cancer Care, Inc. because that is our central purpose - - we leave the "cure" to others.

Enclosed you will find a copy of a release about Miss Buckley's recent testimony before the House Ways and Means Committee, as well as a copy of the full, written testimony. I hope you will find time to absorb the facts in support of our carefully taken position in the matter of National Health Insurance.

We are concerned about some of the proposed tax reforms, which might effect voluntary giving. We pay careful attention to legislation which might effect our tax exempt status and the deductibility of contributions.

cancer CARE, inc.



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Mr. Jimmy Carter

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July 31, 1974

Although we do not expect to be in Atlanta in the near future, we appreciate your invitation and will remember it for the future.

Sincerely,

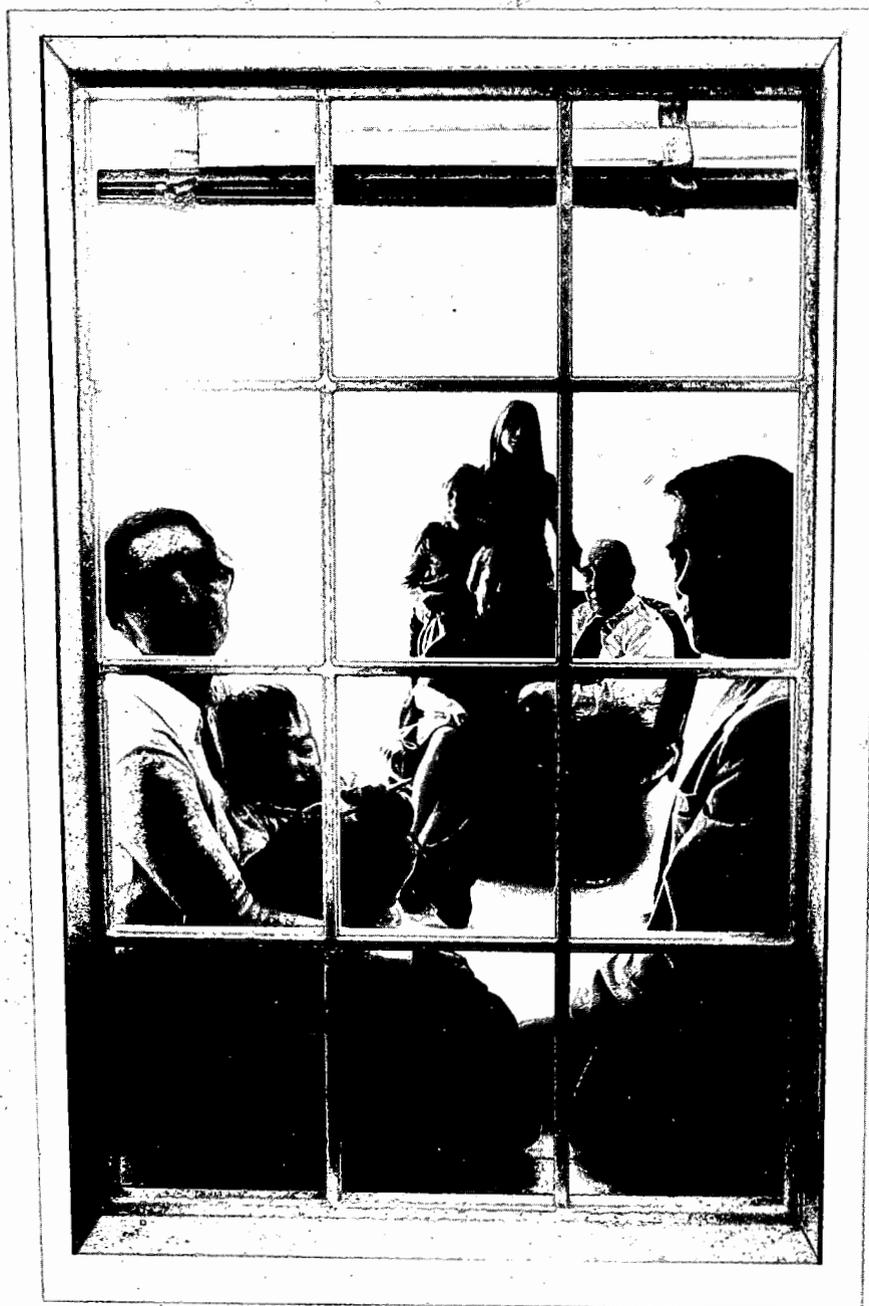
Mary Overton
Assistant Executive Director

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cc: Irene G. Buckley

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STATEMENT ON NATIONAL HEALTH INSURANCE LEGISLATION WITH EMPHASIS ON PROVISIONS FOR COVERAGE OF LONG-TERM CATASTROPHIC ILLNESS

Testimony by Irene G. Buckley, Executive
Director, on behalf of the National
Cancer Foundation, Inc., and Cancer Care,
Inc., before the Committee on Ways and
Means, U. S. House of Representatives,
Friday, June 14, 1974.

IRENE G. BUCKLEY
Executive Director



National Cancer Foundation, Inc. -- Cancer Care, Inc.

SUMMARY OUTLINE OF TESTIMONY ON NATIONAL HEALTH INSURANCE

- I. THIS STATEMENT IS CHIEFLY BUT NOT ENTIRELY CONCERNED WITH THOSE ASPECTS OF NATIONAL HEALTH INSURANCE WHICH RELATE TO CATASTROPHIC ILLNESS.
 - A. Nature of the Agency's Service
 - B. Basis for Opinions Expressed in Testimony Experience and Research

- II. THE NATIONAL CANCER FOUNDATION, INC. AND CANCER CARE, INC. BELIEVE THAT ADEQUATE INSURANCE COVERAGE IS THE ONLY MEANS BY WHICH MOST AMERICAN FAMILIES CAN MEET THE DEVASTATING COSTS OF LONG-TERM CATASTROPHIC ILLNESS.
 - A. Inadequacy of Current Insurance Coverage

- III. CATASTROPHIC ILLNESS COVERAGE SHOULD BE AN INTEGRAL PART OF A COMPREHENSIVE PLAN FOR NATIONAL HEALTH INSURANCE. IT SHOULD NOT BE A SEPARATE AND INDEPENDENT PROGRAM.
 - A. Need of Health Insurance for the Entire Family and Every Family
 - B. Inadequacies of the "Disease-by-Disease" Approach
 - C. Difficulties of Catastrophic Illness as an Option in a Comprehensive Plan
 - D. Financial Advantages of Spreading Costs Over Total Population

- IV. WE FIND THAT LEGISLATIVE PROPOSALS FOR NATIONAL HEALTH INSURANCE SUBMITTED TO THE CONGRESS SO FAR DO NOT MEET ADEQUATELY THE COSTS OR COVER THE SERVICES APT TO BE REQUIRED FOR LONG-TERM CATASTROPHIC ILLNESS.

CATASTROPHIC ILLNESS INSURANCE CANNOT BE MERELY AN EXTENSION OF COVERAGE FOR THE USUAL HAZARDS OF SICKNESS AND ACCIDENT. THERE ARE SPECIAL FACTORS CAUSING OR ACCOMPANYING CATASTROPHIC ILLNESS WHICH MUST BE FULLY STUDIED AND UNDERSTOOD IN MAKING PROVISION FOR THIS TYPE OF COVERAGE.

OUTLINE OF TESTIMONY -- PAGE 2

- A. Duration of Illness
 - B. Age and Family Position of Patient
 - C. Family Income Related to Age and Size of Family Members
- V. WE ARE IN PRINCIPLE OPPOSED TO PAYMENT OF DEDUCTIBLES AND CO-INSURANCE AS A PART OF A NATIONAL HEALTH INSURANCE PLAN. IN CASES OF LONG-TERM CATASTROPHIC ILLNESS THESE PAYMENTS ARE IMPRACTICAL, IMPOSING UNJUSTIFIABLE AND OFTEN IMPOSSIBLE FINANCIAL BURDEN ON THE PATIENT AND HIS FAMILY. THE BURDEN IS COMPOUNDED BY THE POTENTIALLY LONG DURATION OF THE ILLNESS AND THE FACT THAT THE PATIENT IS VERY OFTEN EITHER THE PRINCIPAL WAGE EARNER OR THE WIFE AND MOTHER.
- VI. COVERAGE FOR POST HOSPITAL CARE IN MOST OF THE PROPOSED PLANS IS WOEFULLY INADEQUATE FOR LONG-TERM ILLNESS. EITHER THE SERVICES REQUIRED FOR CARE OF A SERIOUSLY (OFTEN TERMINALLY) ILL PERSON ARE NOT INCLUDED UNDER INSURANCE COVERAGE, OR ARE SO LIMITED IN AMOUNT AS TO PROVIDE ONLY TOKEN PAYMENTS.
- A. Doctor and Hospital Bills
 - B. Care in an Extended Care Facility or in the Home
- VII. WE BELIEVE THAT UNDER NATIONAL HEALTH INSURANCE, PLANS FOR CATASTROPHIC ILLNESS MUST INCLUDE PROVISIONS WHICH ARE SUFFICIENTLY FLEXIBLE TO MEET THE PATIENT'S INDIVIDUAL NEEDS, DEPENDING ON THE NATURE OF CARE REQUIRED AND THE STAGE OF THE ILLNESS.,
- CARE IN THE HOME AS WELL AS IN A HOSPITAL OR OTHER HEALTH FACILITY SHOULD BE INCLUDED.
- VIII. WE ARE WELL AWARE OF THE URGENT NEED MANY FAMILIES FEEL FOR THE FINANCIAL RELIEF WHICH THEY MIGHT GET FROM A NATIONAL HEALTH INSURANCE PLAN PASSED BY THIS SESSION OF CONGRESS. HOWEVER, WE CANNOT RECOMMEND THE PASSAGE OF ANY BILL WHICH DOES NOT MEET THE REALITIES OF THE COSTS OF LONG-TERM CATASTROPHIC ILLNESS.
- IX. WE STAND READY TO GIVE ANY ASSISTANCE POSSIBLE IN FURTHER CONSIDERATION OF THE POINTS WE HAVE RAISED IN OUR TESTIMONY TODAY, TO AID MEMBERS OF THIS COMMITTEE OR INDIVIDUAL SPONSORS OF NATIONAL HEALTH INSURANCE LEGISLATION.

STATEMENT ON
NATIONAL HEALTH INSURANCE LEGISLATION
WITH EMPHASIS ON PROVISIONS FOR COVERAGE
OF LONG-TERM CATASTROPHIC ILLNESS

TESTIMONY BY IRENE G. BUCKLEY, EXECUTIVE DIRECTOR,
ON BEHALF OF THE NATIONAL CANCER FOUNDATION, INC.
AND CANCER CARE, INC. BEFORE THE COMMITTEE ON WAYS AND MEANS
U.S. HOUSE OF REPRESENTATIVES
FRIDAY, JUNE 14, 1974

Mr. Chairman and members of the Committee: My name is Irene G. Buckley, Executive Director of the National Cancer Foundation and its service arm, Cancer Care, Inc.

We appreciate the opportunity to express our views on that part of National Health Insurance with which these agencies are directly involved.

THIS STATEMENT IS, THEREFORE, CHIEFLY BUT NOT ENTIRELY CONCERNED WITH THOSE ASPECTS OF NATIONAL HEALTH INSURANCE WHICH RELATE TO CATASTROPHIC ILLNESS.

Nature of the Agency's Service

Cancer Care, Inc. is a unique service agency in the health care field. Its purpose is to help patients and families cope with multifaceted problems of caring for an advanced cancer patient at home. These patients have usually been dismissed from further intensive in-patient hospital care. They must return home, enter a nursing home or other extended care facility, or make some special arrangements. Most patients want to return home, if possible.

It is usually at the point of the patient's imminent return home that referral is made to Cancer Care, Inc., often by the

social service department of the hospital.

Providing adequate and appropriate care for a seriously ill patient at home is itself a problem. Maintaining an orderly household with normal family relationships and a positive emotional environment may be even more difficult.

Household management is more complicated when there are children, when a parent is the patient and other adult members of the family must work. These heavy responsibilities often fall on persons who are unfamiliar with helping resources in the community, and who are worried over costs which have strained or drained family financial resources. There is, above all, the emotional stress of day and night contact with a family member who is seriously ill and often in great pain.

A staff member of Cancer Care, Inc. helps the responsible member of the family work out a feasible plan for care at home taking into account such factors as the family constellation, financial situation, condition of the patient, and prognosis of the physician. The agency then arranges whatever assistance is needed in carrying out the plan, making a budget, and helping to secure the special services needed. If necessary some portion of the cost is borne by the agency.

Basis for Opinions and Recommendations
Expressed in Testimony Experience and Research

I would, therefore, stress that the opinions and recommendations expressed here about catastrophic illness coverage as part of a plan for national insurance coverage are based on 27 years of

intimate day-to-day contact with advanced (usually terminal) cancer patients being cared for at home.

This experience is further buttressed by an in-depth study of a selected number of client families in which the patient had died within the preceding 16 months.

A copy of the study report entitled, "The Impact, Costs and Consequences of Catastrophic Illness on Patients and Families,"¹ has been provided for each member of the Committee.

The study gathered data in the five general areas of:

1. Income and composition of the family
2. Duration of the illness from onset to death
3. Total costs of the illness, by category
4. Sources of funds to pay the costs of the illness, by category
5. Hardships, other than financial, related to the illness

This social research is a revelation of what it means to total families to have a member stricken with a severe, irreversible illness. It shows that middle-income families can be reduced to poverty in less than two years.

Catastrophic illness means catastrophic costs -- which most families are unable to pay.

Participants in the study were self-maintaining families with middle to low incomes, who are covered by private medical insurance and who are responsible income producers -- accustomed to and

¹The Impact, Costs and Consequences of Catastrophic Illness on Patients and Families, Cancer Care, Inc. of the National Cancer Foundation, Inc., New York, N. Y. March, 1973

expecting to pay their bills. The question, "Why must catastrophic illness bankrupt the middle-class family?" deserves an answer.

The purpose of the research was to document facts on behalf of the families faced with catastrophic illness defined by our agency as "An illness that the patient and his family are not able to cope with, using the attitudes, machinery, and resources normally available. Such an illness has no apparent satisfactory conclusion, and can lead to the exhaustion of both the patient's and family's emotional and financial resources, or to the patient's death."

Some of the major findings of the study will be cited in this testimony to support the agency's views on those provisions of National Health Insurance bills under consideration, pertinent to catastrophic coverage.

THE NATIONAL CANCER FOUNDATION AND CANCER CARE, INC. BELIEVE THAT ADEQUATE INSURANCE COVERAGE IS THE ONLY MEANS BY WHICH MOST AMERICAN FAMILIES CAN MEET THE DEVASTATING COSTS OF LONG-TERM CATASTROPHIC ILLNESS.

Some form of medical insurance was the main source of funds for most families in our study. Only 3% of the study group were without any form of medical insurance. The median picture of these families showed that illness-related costs amounted to \$19,054, the median annual income available to pay these costs was \$8,000, and the median medical insurance payments were an insufficient \$5,000 -- a \$14,000 gap! Can you picture being faced with medical bills amounting to two or three times your annual income? Note that in addition, the expenses for food, clothes and shelter for the family that had to be paid out of this

same income. The 115 families (448 people) in the study expended almost 2 1/2 million dollars just to sustain and care for their family members who were dying from advanced cancer. This did not include the voluntary dollars contributed for professional social work services which all these families received.

Inadequacy of Current Health Insurance Coverage

Total illness-related costs over \$10,000 were incurred by 84% of the study families but only 39% received medical insurance payments of that amount or more. Specific examples indicated the inadequacy of most insurance coverage. One family with an income of \$11,000 had medical costs of \$43,000. About one-half was paid by Blue Cross/Blue Shield and a special health policy. But a family loan of \$12,000 was required to pay the additional costs. In another case, illness lasting nine months cost \$15,675. About one-quarter was paid by health insurance. Those without adequate insurance used savings, cashed in life insurance policies, mortgaged property, took out bank loans, and utilized so much current income for medical bills that the family could have only bare necessities. The father of several children with a normally sufficient income was obliged to use \$15,000 of his savings, borrow substantial amounts, and was left with nearly \$8,000 in unpaid bills at the end of his wife's illness covering more than five years. He stated that insurance paid \$12,000 for hospital bills, but they amounted to \$20,000. His doctor's bills amounted to another \$20,000.

Sometimes, when Cancer Care is trying to help the family

work out a budget, unpaid bills for patient care and running the household are brought to the office in shopping bags.

CATASTROPHIC ILLNESS COVERAGE SHOULD BE AN INTEGRAL PART OF A COMPREHENSIVE PLAN FOR NATIONAL HEALTH INSURANCE. IT SHOULD NOT BE A SEPARATE AND INDIVIDUAL PROGRAM.

The agency takes a strong position on this point for the following reasons:

Need of Health Insurance for the Entire
Family and Every Family

Our experience indicates that health insurance is needed for the entire family and for every family. Ability to secure and pay for adequate medical care in the early stages may prevent serious trouble later. The agency's study also revealed a surprising number of multiple health problems. The patient may have several diseases at the same time, for example, diabetes and heart disease in addition to cancer. Also, in many of the cases there were other health problems in the family at the same time.

A husband had a coronary one month after his wife became ill with cancer. He was unable to work for five months, and only then for shorter hours and less pay. A wife suffered a coronary after the first two years of her husband's illness. In a family of four adults, in a short space of time one died, one became seriously ill with cancer, another had a serious back ailment, and the fourth

"fell apart" from fatigue and tension and required psychiatric care.

One woman suffered recurrence of psychiatric problems when her husband became ill with cancer.

The recurring instances of need for psychiatric help for the patient and family members, particularly children; and the reports of neglect of dental care further illustrate the need for a genuinely comprehensive insurance coverage for preventive care as well as illness.

There is also a danger that catastrophic illness insurance might be considered a substitute for a comprehensive plan to meet the health needs of all persons.

Inadequacies of a Disease-by-Disease Approach

We believe that a "disease-by-disease" categorical approach, oriented to catastrophic illness insurance (such as the coverage recently provided to patients with severe kidney disease), is unsound, impractical and uneconomical. Cancer Care provides a disease oriented service. We believe, however, that the overall impact of the many illnesses appropriately described as catastrophic are apt to be similar in kind, and degree regardless of the disease. Furthermore, the competition for securing insurance coverage among disease oriented agencies would be wasteful in money, time, energy, and emotion. Also it is obviously unfair as a national policy to give preferential benefits based on the nature of an illness suffered by an individual.

Difficulties of Catastrophic Illness
Coverage as an Option in a Comprehensive Plan

On making catastrophic illness coverage an option in a National Health Insurance plan would inevitably result in uneven coverage, with many families unwisely preferring to take the risk of a costly illness rather than pay the additional premium. Too many people, in good health, tend to consider catastrophic illness as happening to other people, but not to themselves. For other individuals the possibility of a long, expensive illness and the fear of not being able to pay for it results in a constant underlying anxiety and a lifetime, spent in accumulating savings "for a rainy day," often at the sacrifice of education of children and other essentials of life.

Financial Advantages of Spreading Costs
Over the Total Population

In the long run, combining coverage of catastrophic illness with the normal amount of illness experienced by individuals is said by some authorities to be sound financially. We lay no claim to expertise in medical economics. However, we have been apprized of expert opinion that spreading the large expenditures of catastrophic illness suffered by a relatively small number of people over the total population will make the cost of such insurance feasible.

Jerome Pollack, Professor of Economics of Medical Care, and Associate Dean for Medical Care Planning, Harvard Medical School, speaking at a Cancer Care, Inc. Symposium, suggested that although individual costs of catastrophic illness are great, they are not

incurred by a large proportion of the population, and that if included as part of a National Health program (which would also presumably lower the incidence of catastrophic illness through better methods of prevention and medical treatment) would not add so greatly to the total cost of the program as to make this kind of coverage prohibitive.

In conclusion, he said, in discussing National Insurance for catastrophic illness:

"We will be required to expand risk sharing to ease and even the burden....Our coverage has tended to address itself not to the truly catastrophic but rather to the median section of loss....The additional cost of extending protection to cover the truly catastrophic illness is minimal."

We, therefore, urge the Congress, in planning for health insurance for the nation, to consider the needs of the total population. Even if it must be implemented in stages, let the master plan be comprehensive and all inclusive.

WE FIND THAT LEGISLATIVE PROPOSALS FOR NATIONAL HEALTH INSURANCE SUBMITTED TO THE CONGRESS SO FAR, DO NOT MEET ADEQUATELY THE COSTS OR COVER THE SERVICES APT TO BE REQUIRED FOR LONG-TERM CATASTROPHIC ILLNESS.

CATASTROPHIC ILLNESS INSURANCE CANNOT BE MERELY AN EXTENSION OF COVERAGE FOR THE USUAL HAZARDS OF SICKNESS AND ACCIDENT. THERE ARE SPECIAL FACTORS CAUSING OR ACCOMPANYING CATASTROPHIC ILLNESS WHICH MUST BE FULLY STUDIED AND UNDERSTOOD IN MAKING PROVISION FOR THIS TYPE OF COVERAGE.

There are many such factors which appear to have been overlooked in framing the catastrophic illness sections of national health insurance proposals, but were clearly revealed in Cancer Care, Inc.'s study. Three of these are duration of the illness; the age and family position of the patient; and the family income in relation to the size of the family.

Duration of Illness

In one-fifth of the cases studied by Cancer Care, Inc., the illness lasted less than a year; in nearly one-fourth of the cases, it lasted four years or more. A few patients in Cancer Care, Inc.'s caseload have been ill for as long as ten years. In most situations, the costs, financial as well as physical and emotional, are cumulative.

Age and Family Position of the Patient

The ages of patients at death ranged from six to 89. The median age was 60. Nearly one-third were over 70. Most of these were elderly couples or persons living alone. Often they had used their Medicare lifetime reserve for hospital care, and the limited number of home visits were inadequate for their needs. Their resources were slightly above the eligibility line for Medicaid. They were sometimes afraid of "not dying soon enough." For example, an elderly couple living on \$3,100 a year incurred \$35,000 in medical bills after

the husband contracted cancer. They exhausted their life savings, sold their house and tapped every other resource of income to pay the bills. After spending \$26,000, they were finally penniless and qualified for Medicaid, which picked up \$8,500.

Nearly 4/5 were in the age range from 30-64, the most active years when family responsibilities are greatest. More than one-fourth were heads of households and chief wage earners. The family income usually stopped entirely or was greatly reduced when the wage earner became ill. In some cases inability to work meant also cancellation of health insurance carried by the employer.

In nearly half the cases, the wife of the wage earner was the patient. This situation usually calls for someone to assume household duties. Other family members -- husbands, mothers, mothers-in-law, sisters, adult daughters, frequently with families of their own to care for -- try to fill the gap.

Many times the breadwinner must stay home from work to care for the children, care for and transport the patient for treatment. The hiring of helping persons in a home eventually becomes a necessity, not anticipated, planned and seldom covered by insurance.

As patients become progressively incapacitated and unable to care for themselves, family members are pushed to their perimeters of perseverance. They are simply unable to cope.

More than one-half of these families in the study lost part or all of their income as a direct result of the catastrophic illness, either through the patient's inability to continue to work, or because another family member had to stop, or cut back, on his job to take care of the patient.

Family Income Related To Size and Age of Family Members

Income during the year before the death of the family member showed this group to be in the middle and lower income brackets. More than one-fourth had incomes of under \$5,000 and only 15 percent were in the \$15,000 and over bracket.

About one in ten were one-member families, usually widowed and living alone.

There were a number of large families of 5 - 7 members, but size of family bore little relation to income. On the whole, these families were barely able

to survive on their incomes. In families with young children, emotional, psychiatric, and adjustment problems were most frequently experienced. There were difficulties in maintaining positive mental health in the face of the stresses brought on by the fact of advanced cancer in a close family member. A large majority of families found it necessary to cut back on usual expenses for food, clothing, and health care of other family members. Other families used money that had been allocated for further education, or travel or little luxuries to provide for patient needs.

The findings of the study and the day-to-day experience of the Cancer Care, Inc. staff show the effects on family members in contact with a critically ill person plus the need for stringent economy are often "devastating."

Children become frightened and confused. Children who have been very close their parents are reluctant and need to be prodded to even enter the sickroom.

They become confused by changes in personality, frightened by physical deterioration, withdrawn and insecure about their own lives and relations with other people.

In many cases, children's schoolwork suffers. Formerly good students make failing grades. Some refused to go to school at all. Confusion and difficulty in concentrating while studying sometimes precipitates actual deterioration in schoolwork. Others become recluses.

Numbers of teen-agers require psychotherapy. One boy refused to finish high school after his mother's death and remained in his room day and night. He moved from his home and his father arranged for psychiatric treatment for him. A teen-age girl had to be in a psychiatric hospital for a year after her mother died. The illness had lasted nine years -- most of the daughter's life.

Nearly 2,500 children lived in the homes of patients served by Cancer Care, Inc. last year.

Among adults the most common results were utter fatigue and frustration.

A woman wrote of being "at her wit's end," needing to work but unable to, her weight reduced to 85 pounds, having stayed up to care for a relative for months from 4:30 p.m. to 8:30 a.m., after the medical homemaker was dismissed for the night.

Care for one patient required change in life plans for four people in the family. The husband took a night job on weekends to add to his income. A daughter who had worked full time and gone to college three nights a week dropped the courses. Another daughter spent full time at college and worked on weekends. The patient's mother, who had health problems of her own, stayed to help out. The patient expected the family to spend all free time at home. Calls from the patient, extra laundry and housework resulted in constant fatigue and family

tensions mounted.

Elderly people often had special problems of coping, both personal and financial. A husband, aged 74, still employed, reluctantly gave up his job to care for his wife, and used savings to pay for the medical expense.

An elderly woman started to work full time, with the help of a medical homemaker to care for her husband. However, she had to retire before she became eligible for a company pension and her husband's union pension stopped with his death. She was left with Social Security of \$154.80 a month, living in an apartment for which rent was \$157.00 a month. She reported unpaid bills owing to six doctors.

In the fiscal year 1973, patients aged 65 and over comprised 47 percent of Cancer Care, Inc.'s caseload.

WE ARE IN PRINCIPLE OPPOSED TO PAYMENT OF DEDUCTIBLES AND CO-INSURANCE AS PART OF A NATIONAL HEALTH INSURANCE PLAN. IN CASES OF LONG-TERM CATASTROPHIC ILLNESS THESE PAYMENTS ARE IMPRACTICAL, IMPOSING UNJUSTIFIABLE AND OFTEN IMPOSSIBLE FINANCIAL BURDEN ON THE PATIENT AND HIS FAMILY. THE BURDEN IS COMPOUNDED BY THE POTENTIALLY LONG DURATION OF THE ILLNESS AND THE FACT THAT THE PATIENT IS VERY OFTEN EITHER THE PRINCIPAL WAGE EARNER OR THE WIFE AND MOTHER.

We are aware that the costs of a system of national health services available to every citizen must of necessity be paid for by the citizens, whether by greater Social Security, a separate health payroll tax, part payments of insurance costs, or direct payment to vendors by individuals. In our opinion the payment of deductibles and co-insurance is a complicating factor, adding to administrative costs. In some borderline cases of poverty and near-poverty such payments may tend to discourage persons from seeking the medical help they need but cannot afford. These payments up to the annual amounts required by the current proposals before catastrophic coverage takes effect, we find too great a financial burden for the families which Cancer Care, Inc. is involved. The payment of 10 percent of income or annual expenditures of \$1,000 to \$5,000 may not seem impossible amounts for a single year, but if the illness continues year after year, cumulative effects may cause severe financial burden.

We therefore request that the three factors mentioned above, namely the duration of illness, family position of the patient, and family composition as related to family income be taken into

account before requiring premium payments, deductibles and co-insurance payments in cases of catastrophic illness.

COVERAGE FOR POST HOSPITAL CARE IN MOST OF THE PROPOSED PLANS IS WOEFULLY INADEQUATE FOR LONG-TERM ILLNESS. EITHER THE SERVICES REQUIRED FOR CARE OF A SERIOUSLY (OFTEN TERMINALLY) ILL PERSON ARE NOT INCLUDED UNDER INSURANCE COVERAGE, OR ARE SO LIMITED IN AMOUNT AS TO PROVIDE ONLY TOKEN PAYMENTS.

Hospital and Doctor Bills
Even When Insured Without Limit Are Not Enough

They are, of course, large items in catastrophic costs. They were reported as major cost items by every family in the Cancer Care study. Hospital costs ranged from under \$2,500 to over \$30,000; doctors' and surgeons' bills from \$200 to over \$5,000. Overall these expenses amounted to nearly two-thirds of the total costs directly attributable to the services required for care of these patients. Some, but not all, of the plans introduced in Congress call for unlimited coverage of these two items, and are believed to provide catastrophic coverage. However, there are great variations as to what the proportion of total cost is payment for doctor and hospital.

In one of our cases the total cost of the illness was reported as \$13,783, of which doctor and hospital were responsible for \$5,472. Other expenses amounted to \$8,311. In another case, doctor and hospital costs of \$4,000 amounted to less than a third of total costs of \$12,230. In yet another case, total care for an illness lasting 3 years cost \$30,588, of which only \$4,000 were

due to doctor and hospital costs. In an illness covering an extended period, relatively small proportion of the time is apt to be spent in a hospital. Patients are usually dismissed when they no longer benefit by hospital care. It is important for framers of health insurance legislation to understand that patients may be discharged from the hospital when they are still very ill indeed. They are often terminal patients who literally go home to die.

Care In An Extended Care Facility Or In The Home

The inadequacy of the provisions for care outside the hospital can best be understood by analyzing the range of services received by a patient in a hospital. In addition to doctor, nurse service, laboratory and therapy of various kinds, the patient receives food (purchased, prepared and served) shelter (with daily cleaning and linen change), bathing and grooming, laundry, transportation (by wheel chair if necessary). A social worker is usually available. A bedside library, and small errand service are often available. After the hospital stay, most of these services are still necessary, and if the patient cannot do them for himself, they must be provided or somehow secured.

While the four usual costs were anticipated -- doctor, hospital, drugs and burial, at least 23 other services usually not anticipated and not covered by insurance are:

MEDICAL HOMEMAKER
HOUSEKEEPER
HOME ATTENDANT
NURSE
DOMESTIC
SOCIAL WORKER
EQUIPMENT
LABORATORY TESTS
PATIENT TRANSPORTATION
SPECIAL TREATMENT
OTHER PATIENT CARE
FOOD FOR HOME HELP
BLOOD TRANSFUSIONS
PATIENT LAUNDRY
DENTIST
SPECIAL DIETS
SPECIAL CLOTHING
PSYCHIATRIC TREATMENT
DWELLING MODIFICATIONS
NURSING HOME
CHILD CARE
EXT. CARE FACILITY
PATIENT PERSONAL CARE

If the necessary items for care in the hospital are covered by hospital insurance, though they are not usually labeled "health" services, the question may logically be raised as to why the services essential for adequate care of a catastrophically ill person cannot be covered after he leaves the hospital.

These unanticipated items for care in the home may run into very high costs. For example, if the wife and homemaker is the patient, a substitute for family care and housekeeping must be provided at considerable cost. So far this kind of service has not been included as a legitimate medical expense in any National Health Insurance plan. Since household workers are now covered under a minimum wage, 8 hours a day coverage for a housekeeper would cost nearly \$6,000 a year. A trained homemaker-home health aide for 4 hours a day would cost about the same amount.

Among the costs for such items to families studied, one family paid \$10,800 for skilled help at home during a period of 3 years and 5 months; another paid \$8,688, for a housekeeper and homemaker for 3 years; drugs cost \$1,700, and psychiatric care and counseling cost \$1,250.

Care in a nursing home when included in benefits is covered for periods of 30 to 120 days per year. If continuous care is required, the total cost soon becomes prohibitive for the average family. The only alternative would seem to be care in the home. But home care ser-

vices too are limited as to specific services such as registered nurse, home health aide, speech or physical therapist, in some cases, a social worker. Moreover, the number of home visits is also limited. Usually only a total of 100 visits per year, or in one plan, 200 visits are covered by insurance, plus co-insurance.

WE BELIEVE THAT UNDER NATIONAL HEALTH INSURANCE, PLANS FOR CATASTROPHIC ILLNESS MUST INCLUDE PROVISIONS WHICH ARE SUFFICIENTLY FLEXIBLE TO MEET THE PATIENT'S INDIVIDUAL NEEDS, DEPENDING ON THE NATURE OF CARE REQUIRED AND THE STAGE OF THE ILLNESS.

CARE IN THE HOME AS WELL AS IN A HOSPITAL OR OTHER HEALTH FACILITY SHOULD BE INCLUDED.

We believe that social services should be an integral part of such care. The nature of home care service should be planned in relation to the changing needs of the patient and the capacity of the family to provide for such needs.

Plans for care may be made and periodically reviewed by an appropriate agency or a professional team which might include some or all of the following: physician, psychiatrist, nurse, social worker and therapist. Those services deemed essential by such a team to the well-being of the patient should be covered in any national health insurance act.

As indicated at the outset of this statement, Cancer Care, Inc. program provides a direct service to the patient being cared for at home and to their families. The agency

provides social work counseling to help advanced cancer patients and family members cope with the emotional trauma of the disease, and financial planning and assistance when needed to help pay for the costs of home care. The service program is geared to individual patient and family need according to a financial and service plan worked out by the agency with responsible family members. One important feature in each plan is flexibility to provide the special service needed according to changing needs of the patient over a period of time. A trained nurse is provided for when needed. But nurses are not and should not be employed when the real need is for a housekeeper.

Within a 50-mile radius of New York City, in 1973, Cancer Care, Inc. spent over two million dollars for services on behalf of advanced cancer patients and their families, including social work counseling, planning and information, financial aid, social research and professional education and training.

Of this total, over \$936,000 was dispensed to help families pay for 600,000 hours of services needed for home care. Among services provided were homemaker-home health aides, 414,000 hours; housekeepers and domestics, 120,000 hours; attendants, 30,000; and nurses, 24,000 hours.

We realize that the variety of services utilized and the flexibility with which they are used is not easy to incorporate into a federal law. Our Board of Trustees believes that the principles are sound and that they can be incorporated into a system of planning and service which will reflect the variety of health care needs for service.

The position statement of the Board of Trustees of the National Cancer Foundation, Inc. and Cancer Care, Inc. on Catastrophic Illness Insurance As a Part of Comprehensive Insurance, ends with these words:

"In addition to the care by a physician and medical treatment prescribed by him, and the social work counseling, services in the home may need to include any or all of the following among a variety of services: homemaker-home health aides, appropriate household or other help, child care; nursing care; transportation; and provisions of wheel chair or other sick-room equipment."

We hope the legislators who have given so much thought to planning for National Health Insurance programs will be willing to think further about the special needs of those who suffer from long-term catastrophic illness.

WE ARE WELL AWARE OF THE URGENT NEED MANY FAMILIES FEEL FOR THE FINANCIAL RELIEF WHICH THEY MIGHT GET FROM A NATIONAL HEALTH INSURANCE PLAN PASSED BY THIS SESSION OF CONGRESS. HOWEVER, WE CANNOT RECOMMEND THE PASSAGE OF ANY BILL WHICH DOES NOT MEET THE REALITIES OF THE COSTS OF LONG-TERM CATASTROPHIC ILLNESS.

WE STAND READY TO GIVE ANY ASSISTANCE POSSIBLE IN FURTHER CONSIDERATION OF THE POINTS WE HAVE RAISED IN OUR TESTIMONY TODAY, TO AID MEMBERS OF THIS COMMITTEE OR INDIVIDUAL SPONSORS OF NATIONAL HEALTH INSURANCE LEGISLATION.

The National Cancer Foundation, Inc.

ONE PARK AVENUE
NEW YORK, NEW YORK 10016

Contact: Alfred V. Taylor
212/679-5700

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NATIONAL HEALTH INSURANCE PROPOSALS CRITICIZED BY NATIONAL CANCER FOUNDATION

Washington, D. C., June 14 -- All the national health insurance bills currently under consideration by Congress were criticized for failing to cover the high costs of care of long-term catastrophic illness, in testimony given today before the Committee on Ways and Means of the U.S. House of Representatives by Irene G. Buckley, executive director of The National Cancer Foundation and Cancer Care, Inc.

Miss Buckley, representing the large New York based voluntary agency that serves advanced cancer patients and their families stated, "We cannot recommend the passage of any bill which does not meet the realities of the costs of long-term catastrophic illness."

Miss Buckley termed coverage for post-hospital care "woefully inadequate" for long-term illness, in the bills currently under consideration by Congress. "Either the services required for care of a seriously (often terminally) ill person are not included, or are so limited in the amount as to provide only token payments," Miss Buckley declared.

"The question, 'Why must catastrophic illness bankrupt the middle-class family?' deserves an answer," she told the Committee.

(more)



Miss Buckley argued that national health insurance should provide services for care at home such as trained homemakers and social services to help patients and families cope with medical and psychological aspects of catastrophic illness.

The payment of deductibles and co-insurance, provisions of proposals now being considered, also came under attack by Miss Buckley. She stated that experience and recent research of the National Cancer Foundation demonstrate that a middle-income family caring for an advanced cancer patient at home "can be reduced to poverty in two years" time, losing their savings, investments and being driven to bankruptcy by the high cost of care.

Deductibles and co-insurance payments, she said, are "impractical, imposing an unjustifiable and often impossible financial burden on the patient and his family." She pointed out that the patient is very often the principal wage earner or the wife and mother, and, in the case of long-term illness, income is drastically reduced while bills assume mammoth proportions.

Miss Buckley opposed the concept of a separate national health insurance plan limited to catastrophic illness, and also any plan that would allow catastrophic illness coverage to be optional.

"Catastrophic illness coverage should be an integral part of a comprehensive plan for national health insurance," she said. "Our experience indicates that health insurance is needed by the entire family and for every family."

(more)

She stated that the non-profit agency also takes issue with a disease-by-disease categorical approach to national health insurance, such as the coverage authorized by the 1972 Social Security amendments and provided by the Medicare kidney dialysis program. Such an approach is "unsound, impractical and uneconomical," she said.

Miss Buckley said that provision for catastrophic illness must be sufficiently flexible to meet the patient's individual needs, depending on the nature of care required and the stage of the illness, and "the capacity of the individual family to provide for such needs."

She cited the recent study made by the National Cancer Foundation and Cancer Care, Inc. which found that home care of an advanced cancer patient often involves up to 27 indispensable services, most of them unanticipated by the family and not covered by present day medical insurance. These services -- in addition to doctor, hospital, drugs and burial -- included such items as social work counseling, blood transfusions, medical homemaker, housekeeper, special treatments, patient laundry, sickroom equipment, and nursing care.

Calling upon legislators to provide health insurance that is comprehensive and all inclusive, Miss Buckley said that the National Cancer Foundation and Cancer Care, Inc. believe that adequate insurance coverage is the "only means by which most American families can meet the devastating costs of long-term catastrophic illness."

(more)

Miss Buckley stated: "We have been apprised by expert opinion that a spread of the large expenditures of catastrophic illness suffered by a relatively small number of people over the total population will make the cost of such insurance feasible."

The agency's position was based upon its 27 year history of service to advanced cancer patients being cared for at home and their families, according to Miss Buckley.

The National Cancer Foundation and Cancer Care, Inc. are coordinated parts of a single social service agency. The Foundation conducts social research into the impact of the illness on patients and families and carries out programs of public and professional education. Cancer Care, Inc., the in-person service arm, operates within a 50-mile radius of New York City. Last year the agency provided counseling and financial aid to 23,000 people -- helping advanced cancer patients and their families cope with emotional trauma and economic costs related to care at home.

The agency is headquartered at One Park Avenue, New York City.

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