Traveling for Care

Robust research is underway at many prestigious national cancer centers. This means that there might be times when, after you have researched progress in treating your illness, you realize that the best care for your particular type, stage, and grade of cancer is provided at a major treatment center away from home—perhaps very far from home.

This, of course, adds several layers of complexity to your treatment plans, not the least of which are financial considerations. Some health insurance policies cover airfare but not lodging; some pay a per diem to apply to food and lodging, but do not cover airfare; still others pay only so much per travel mile. Some policies pay nothing for travel and lodging.

Assess needs and benefits

Your first step should be to verify what travel expenses your health policy will cover, because this coverage varies greatly.

Next, do some planning. If airfare isn't reimbursed by your health policy, driving might be an option. Driving may be out of the question, though, if the distance is great, if your car isn't in such good shape, or if you feel just plain awful. Lodging for family members who go with you is yet another expense. And who will remain behind? If children accompany you or a sick sibling, what about their schooling?

Air travel

In many instances, the only practical way to travel to the treatment center of your choice is by air. There are charitable groups that exist to fly you, free of charge, to distant treatment centers.

Some of these groups have requirements—for example, that the patient be able to embark and disembark the plane without airline assistance or that support equipment, if needed, be manageable without airline intervention.

Each service is described below, but the best starting point if you're pressed for time is Mercy Medical Airliff's National Patient Air Transport Helpline (NPATH), the only national toll-free number that can direct patients to the nearest and best air travel resource for their travel needs: (800) 296-1217.

Mercy Medical Airlift. Mercy Medical Airlift is the coordinating organization for three sectors of charitable air services in the U.S. They utilize fixed-wing (not helicopter) aircraft to help financially needy patients go to and from care centers for previously scheduled evaluation, diagnosis, treatment, and rehabilitation appointments. They do not provide emergency transport.

The three sectors of aviation involved in MMA are:

- The corporate aviation sector, consisting of 750 corporations who allow cancer and multiple sclerosis patients to use empty seats on regularly scheduled flights. The Corporate Angel Network is the focal point for this program. In 1997, 900 patients were transported. You do not need to demonstrate financial hardship to use CAN; there is no limit on the number of trips you can make. Cancer patients, their companion, or bone marrow donors are eligible. Children may be accompanied by two parents. Patients must be able to walk up stairs to board the plane without assistance, and must be able to fly without any form of life support or medical assistance. Call (914) 328-1313 for other requirements.
- The private aviation sector, consisting of 4,500 pilots within thirty-two volunteer pilot organizations across the U.S. who use their own time and aircraft to fly patients free of charge to care centers. Organizationally, these groups cluster under Air Care Alliance. In 1997, more than 8,000 patients were transported. You may call ACA at (888) 662-6794 in the U.S.
- The commercial airline sector. Several commercial airlines offer, at times, special ticket prices or free tickets to those who need to travel for medical care but cannot afford full ticket prices. These special offers vary by airline and are not necessarily ongoing offers.

In addition, Mercy Medical Airlift operates the Patient Assistance Center (PAC); (888) 675-1405), whose programs are:

• The National Patient Air Transport Helpline (NPATH)

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is, as mentioned earlier, the only national toll-free number that can direct patients to the nearest and best air travel resource for their travel needs. Call (800) 296-1217.

- Special-Lift and Child-Lift Programs to assist with transport of those needing care for pediatric or rare diseases at medical research centers.
- Programs to develop the charitable services of the private air sector, under the auspices of the Air Care Alliance.
- Programs to encourage and unify charitable ticket use programs among the commercial airlines.

The Red Cross. For military personnel only, the Red Cross can assist with emergency travel and communication. Call (202) 728-6400, or their 24-hour line at (202) 728-6401 to find the chapter nearest you or your destination.

Mission Air Transportation Network. This Canadian group uses corporate, government, or commercial aircraft to fly Canadians who cannot afford air transport but need medical care. Call (416) 222-6335.

Mission Aviation Fellowship. MAF supports air ambulance services and medical assistance in 57 countries. Call (909) 794-1151.

Land travel

Fewer organizations exist to help with land travel than for air travel.

American Cancer Society. The ACS regional offices in many cities have networks of volunteers who can provide transport by car to and from your treatment center. Call your local office or (800) ACS-2345.

The Leukemia Society of America. For patients with leukemia, lymphoma, Hodgkin's disease and myeloma, LSA can provide up to \$750 in assistance per year for travel and other services, such as reimbursement for specific, approved drugs, blood transfusions, or x-rays. Only bills incurred after you have applied to LSA for aid are eligible for reimbursement. Call (800) 955-4LSA.

Traveler's Aid Society. Traveler's Aid provides emer-

gency travel and lodging for those in dire financial need. Check local phone books for contact information. For the Traveler's Aid phone number at your destination, check your public library for phone books for other major cities.

Lodging

Having the means to pay for travel for care is part of the solution. However, finding affordable housing remains a barrier to travel for some cancer survivors. Several groups offer lodging for free or for a nominal fee.

Note that the cost of meals usually will be your responsibility. Facilities such as Hope Lodge, however, have kitchens you can use to reduce your expenses by avoiding the higher cost of restaurant meals.

American Cancer Society's Hope Lodge. The American Cancer Society sponsors free lodging in various cities for cancer patients being treated at nearby hospitals and their families. Their service is also offered to non-US citizens traveling within the US for medical care. Lodging is free and is provided on a first-come, first-served basis, so contact the ACS for the phone number of the Hope Lodge nearest the hospital you'll be using to verify that space is available. Each Hope Lodge has kitchen and laundry facilities. Call (800) ACS-2345.

National Association of Hospital Hospitality Houses. NAHHH offers a list of member hotels who provide reduced rates and special services to patients at nearby hospitals. Call (301) 961-3094, (317) 883-2226, or (800) 542-9730.

Ronald McDonald Houses. Ronald McDonald Houses, sponsored by the McDonald's Corporation, offer free lodging to children who must travel for medical care and their families. Pregnant women considered highrisk pregnancies are also eligible. Financial need may be a prerequisite for entry at some sites. A nominal fee of ten dollars a night may also be charged, but this may be waived if financial hardship is demonstrated. Call (312) 836-7100.

Children's Inn at the National Cancer Institute. The National Cancer Institute offers free meals and housing

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for children under age eighteen who are being treated at the NCI. Lodging might also be available for family members on a case-by-case basis. Both US and non-US citizens are accommodated. Call (800) 4-CANCER for more information, or contact:

Peggy Nelson The Children's Inn NCI, 7 West Drive, Bethesda, MD 20814 Phone: (301) 496-5672.

For family members who cannot be lodged at the NCI, the American Cancer Society's Hope Lodge in Baltimore is an alternative, as are nearby hotels who have agreements with the NCI to offer reduced rates to the families of cancer patients treated at the NCI.

Adult care at the National Cancer Institute. Adult patients who have been treated at the NCI report that their spouses were allowed to stay overnight in the patient's room. You should verify this with the NCI and with the nurses on the floor.

Hospital-hotel agreements. Many hospitals have agreements with nearby hotels for reduced rates for patients and families. Contact the hospital's social worker or the admitting desk in advance of traveling for such information.

Hospital outpatient facilities. Some major cancer centers, such as Johns Hopkins in Baltimore, have outpatient lodging run by the institution for those requiring long-term follow-up care, such as that following bone marrow transplantation. Discuss these resources with the hospital admitting staff before you travel. The cost of you and your family staying in such hospital-run facilities may be covered by your insurance policy.

Travel insurance with medical features

Your health insurance might not cover out-of-state emergency medical care, so before you travel for pleasure, you should verify your health policy's coverage. If it's restrictive, consider getting travel insurance that covers emergency medical care. This ensures that if you take a vacation out of state and need, for instance, to

get a transfusion or other emergency care while you're away, you'll have coverage to do so.

Here's a partial list of companies that offer such coverage, although this list does not imply recommendation or endorsement:

• Travel Assistance International: (800) 821-2828

• Medex: (888) MEDEX-00

• Travel Emergency Assistance (TEA): (281) 364-7726

Organizations that help with travel plans

Several groups can help you organize your travel plans for the least expense and worry.

The Leukemia Society of America. The Leukemia Society of America, described above in the section "Land travel" can help with travel arrangements. Call (800) 955-4LSA.

Candlelighters. The Candlelighter Childhood Cancer Foundation can offer much practical and instrumental help with travel and lodging plans. In the US, call (301) 657-8401 or (800) 366-CCCF. In Canada, call (800) 363-1062.

The National Children's Cancer Society, Inc. This independent national organization can provide financial assistance for various needs. Call (800) 5-FAMILY.

Schooling

Some treatment centers, such as the Fred Hutchinson Cancer Center in Seattle, offer on-site schooling for sick children and their siblings. Contact the cancer center you're planning to use to see if they accommodate children who travel for care or who accompany others.

Your child's school, of course, might be willing to design a lesson plan that you can oversee to continue schooling your children who must travel.

Canadian assistance

This section describes Canadian services, some of which also are discussed elsewhere in this fact sheet.

• The British Columbia Medical Services Plan coordi-

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nates sharing travel expenses with commercial transportation firms such as airlines and ferries. Your doctor must fill out a Travel Assistance form. Call (800) 661-2668 or (250) 387-8277.

• The Mission Air Transportation Network uses corporate, government, or commercial aircraft to fly those who cannot afford air transport, but need medical care. Call (416) 222-6335.

• The Canadian Cancer Society offers various forms of assistance. Call (604) 872-4400 or (416) 961-7223.

Canadian Cancer Society resource numbers by province:

• Alberta: (403) 228-4487

• Manitoba: (204) 774-7483

• New Brunswick: (506) 634-6272

• Newfoundland and Labrador: (709) 753-6520

• Nova Scotia: (902) 423-6183

• Ontario: (416) 488-5400

• Prince Edward Island: (902) 566-4007

• Quebec: (514) 255-5151

• Saskatchewan: (306) 757-4260

This fact sheet was adapted from *Non-Hodgkin's Lymphoma: Making Sense of Diagnosis, Treatment, and Options,* by Lorraine Johnston, © 1999 by Patient-Centered Guides. For more information, call **(800) 998-9938** or see *www.patientcenters.com*.