All in the Family

Caregivers can ease their burdens with services and self help

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Families of children with HIV -- whether parents, grandparents or other caregivers -- face a variety of painful issues that make it tough to cope. Social and psychological support services, along with self-help techniques, can relieve many burdens. But even these steps may be hard to take, especially with the stresses of daily life faced by those in poor communities. According to psychiatrists Claude Mellins and Anke Ehrhardt of Columbia University, the social need most frequently expressed by caregivers of HIV positive children is free time for rest, relaxation and addressing their own medical problems, followed by access to support groups and family therapy.

It's critical for caregivers to take their needs seriously and find ways to meet them. Gillian Walker, a social worker at the Ackerman Institute for Family Therapy in New York City, notes that AIDS-affected family members often struggle with the demoralizing effects of shock, fear, shame, denial, anxiety and grief. Service providers emphasize that such feelings are normal and that talking about them can ease the pain. Support groups can be very helpful, but sometimes individual or family therapy is also needed.

Family members can look first to the staff who care for their child and ask for a separate appointment to talk about their own concerns or to refer them elsewhere. If the staff is not helpful, a local AIDS hotline or health department should be able to make referrals. Unfortunately, in many geographic areas, resources are still grossly inadequate, and in order to get help, you may need to become a vocal advocate for better services. (Some national resources may also offer help; see RESOURCES.)

According to Emily Gordon, director of the New York City pediatric AIDS resource group Just Kids, sometimes counselors overemphasize planning for children's futures after caregivers die, at the expense of focusing on the adults' current problems. And they often face many: Insensitivity, prejudice or patronizing attitudes from social workers, health practitioners and teachers; juggling hospital or clinic visits, school appointments and child care for various family members; dealing with confusing medical information and choices; alienation from extended family due to the stigmas of AIDS, drug use or homosexuality; concerns about disclosing a child's or parent's HIV status inside or outside the family; and coping with the death of one or more family members.

But there are ways out. Walker notes that caregivers can often marshal unrecognized strengths such as flexibility, inventiveness or stress management skills. Also, many can draw on ties to

extended family or community. She advises, “People should look for relationships and connections that they may have forgotten or overlooked.”

Spiritual faith and community can be another source of comfort. Mellins and Ehrhardt found that most caregivers considered religion their primary coping strategy. Many communities have pastoral programs that provide support services to families in need.

It may also be helpful to explore wellness techniques that address both mental and physical health. Among the options are meditation, massage and such Asian therapeutic exercises as yoga, t’ai chi and chi kung. In some areas, programs or classes are available to PWAs for free or at reduced rates.

For HIV positive parents dealing with their own mortality, planning for the future care of surviving children (permanency planning) can be stressful. A growing number of states have provisions for standby guardianship, enabling parents to choose their children’s future guardian without giving up any present rights. Parents should contact a legal services center for information.

Recreation programs for children with HIV can do more than just provide family members a break from routine. According to Diane Donovan, a caregiver and director of Positively Kids in Queensbury, New York, these programs can give children happy memories that can sustain them through rough times. “My kids have gone to a camp for HIV positives three years in a row now. After every summer, they talk about it for the next six months. There’s so much love there, and the kids are treated with dignity and respect.” A number of summer camps nationwide offer programs for children with HIV that include medical care and family counseling. And special foundations for seriously ill kids do their best to grant wishes, such as a trip to Disney World.

One often overlooked issue is that of behavior problems -- including depression, anxiety, aggression, hyperactivity and learning disorders -- among both HIV positive children and their HIV negative siblings. Prescribed drugs such as Ritalin may provide relief, but also tend to have such side effects as headaches, insomnia, appetite loss and slowed growth.

As an alternative, some psychologists and holistic health professionals recommend Bach flower remedies -- inexpensive, nontoxic, highly diluted extracts said to help gently ease emotional imbalances. Also, since sugar, dairy products and some food additives can contribute to behavior disorders, caregivers may want to consider dietary change and nutritional supplementation. In short, self-help approaches can be a valuable supplement to limited support services for families coping with HIV.

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