
How To Find The Help You Need

We all know how devastating the diagnosis of Huntington disease (HD) can be to individuals and their families. We also know how difficult it can be for families to adapt to the many changes brought on by the progression of HD. This can produce a great deal of emotional strain. Some may feel they must face these challenges alone. But, this is not necessary. No one should feel they need to deal with this disease alone. There are many resources available to help. Here are some to consider.

Informal Networks

- Family, friends, co-workers and neighbours can be very helpful by visiting, providing companionship for social and recreational outings, helping with household chores, offering transportation to appointments or just being there to listen and support.
- Don't hesitate to ask for help. People may not offer on their own for a number of reasons but are often more than willing to help if asked.
- Community groups such as neighbourhood clubs, professional associations and churches, can play an important role in helping families deal with HD. They may offer a variety of services including children's camps, family retreats, home visiting programmes, weekly discussion groups and recreational activities.

Health and Social Services

- A family doctor can be an important contact. Regular visits with a family physician will not only ensure good general health, but will serve to create a close relationship between doctor and patient, enabling the doctor to be aware of the patient's

overall needs. Often, your doctor will suggest a service or make a referral to a community resource, such as Home Care, occupational therapy, and genetic counseling.

- Wherever you live, there is probably some form of Home Care programme available through your provincial health care system. Home care is a group of services that enable people to live at home for as long as possible, and delay the need to move to a long term care facility.
- Home Care services will vary depending on where you live. Examples of these services include visiting nursing, home support (help with light housekeeping, and cooking), physiotherapy, occupational therapy, social work, respite and personal care (help with dressing, bathing, shaving, etc).
- Contact your family doctor, the local hospital or consult your telephone directory to find out about the home care programme in your area. Many provincial governments have a telephone referral service to help individuals locate provincial programmes. This number can usually be found at the beginning of the provincial government listings section of your local telephone book.
- Private home care agencies provide services similar to the government home care programs. This may be an option worth exploring especially in times of emergency, short notice or as a supplement to the public services.
- Other community services that may be helpful include adult day centres, meals-on-wheels, transportation services, financial assistance, home & yard maintenance, individual and

family counseling, speech and swallowing therapy and emergency response systems. These are some of the more common programmes available in most communities but there may be additional services available to address other more specific needs.

Finding Your Way

In Canada, we are very fortunate to have a vast array of formal programmes available to help individuals and families cope with social problems, disease and other traumatic life events. However, the health care and social service systems can be complex, frustrating and sometimes overwhelming to those in need. An individual with HD and their family may require a number of different services over the course of the disease. Many are unaware of what services are available. Those that are aware may experience difficulty locating the resource that best meets their needs. Here are a few tips to help you navigate the system of community services.

- If a person is enrolled in a provincial Home Care program, there will be a Case Manager or Case Coordinator assigned to provide assistance in assessing need and recommending appropriate supports. They will link you to the services you need.
- The Huntington Society of Canada employs trained social workers in the Resource Centres and IFS program. These social workers have information on community resources that are beneficial to individuals with Huntington disease and their families. They can assist you by assessing what services would be appropriate and providing information needed to access those services. They can also consult with professionals in the community and educate them about HD to ensure that the services they are providing

to families are offered with good understanding of the disease and its effects.

- Another way to learn about helpful resources is through participation in a support group. People in support groups often share information about the services that have helped them.
- If you know the type of service you are looking for, there may be an Information and Referral Centre in your area that can provide you with the name and telephone number of who to contact.

Once you have located the service that you feel can meet your needs, there are a few things that you can do to ensure the first encounter is successful.

- Prior to the first meeting, make notes about the major points you would like to share regarding your situation
- List questions you would like to ask about the program
- Have a family member or friend attend with you
- Be open and honest about your needs

Adapted from: "I know there is help out there, but where do I start", by Sandra Funk (HORIZON, Spring 2000)