

## VTI Level III : Volunteering in Support of the Huntington's Community module

### Introduction

The Huntington Society of Canada was built around the goal of helping people. When individuals with HD and/or their family members come to the Society, they are introduced to an organization that will, quite literally, come into their home to help ensure their well-being.

In the early days, it was all about creating a community where one previously didn't exist. Families who felt isolated from the rest of the world because of HD soon had the opportunity to join a network of families that was growing right across the country. But while Ralph Walker would come to Halifax or Edmonton as often as he could, it was really up to the families who lived there to reach out and support one another.

As the organization got bigger, it became clear that this approach was not sustainable, and that the needs of the HD community went far beyond the ability of volunteers to contend with. Social workers were subsequently hired to meet the needs of families and, over time, the Society has grown to have at least one active social worker in every province of the country.

Formally, volunteers with the Huntington Society are involved in leading the national organization, leading local Chapters of volunteers, fundraising, and public awareness. Informally, members of the Huntington's community continue to provide support to each other in any way that is needed.

We think that there is an opportunity for well-trained HSC volunteers to be *volunteering in support of the Huntington's community* who cannot always help themselves. However, engaging volunteers in this kind of activity is not as straight-forward as having them run a fundraising or public awareness event. Among other things, there are privacy and liability issues that need to be taken into account – these apply to the organization, the individuals and families being served, as well as to volunteer advocates.

In short, we are trying to see if it is possible to expand the range of volunteer opportunities with the Society by expanding into the one area that has been the cornerstone of the organization – helping people.

### What do you mean by *Volunteering in Support of the Huntington's Community*?

We are using the statement *volunteering in support of the Huntington's community* to describe a volunteering opportunity whereby volunteers are working to the direct benefit of someone(s) in their local HD community. Just as a lawyer is responsible for all things associated with the well-

being of their client, we are trying to create a volunteer role where someone can assist and support some aspect of need for a person with HD or family member.

Currently, we have a limited range of specific activities in mind that would need to be fleshed out. These are:

- Visiting a caregiver to provide companionship and “down-time.”
- Visiting a person with HD who is either living on their own, or in an institution.
- Using the local system to obtain food for an individual or family in need.
- Using the local system to obtain clothes for an individual or family in need.
- Using the local system to obtain emergency shelter for an individual or family in need.
- Working with an individual or family to complete the filing of government forms, requests, filings, etc.
- Providing transportation for an individual or family in need.

### **What do you want me to do?**

Each of these activities would require training. We need you to help us make sure that the training we provide is sufficient by identifying issue areas and/or questions that the training materials would need to address in each instance. As a group, we will also need to identify potential pitfalls of this kind of volunteering to make sure that everyone involved – staff and volunteers – are starting this process with their eyes open.

### **When will *Volunteering in Support of the Huntington’s Community* be available to HSC volunteers?**

Here are the steps that we propose:

#### *Step 1*

We are going to hold this VTI Summit in Edmonton and begin the process of working with volunteers to establish what they would need to know, or what information they would need to have access to, in order to work in a controlled way for their HD community.

#### *Step 2*

Based on the outcomes of the VTI Summit, the pilot *Volunteering in Support of the Huntington’s Community* will be made available in one centre to see if it can be made to work. In this case, the intention would be to use interested members of the Edmonton Chapter.

#### *Step 3*

Evaluate the project in Edmonton and figure out what it would take to recreate the successes in another location, and figure out whether any identified weaknesses can be overcome.

#### *Step 4*

Begin the process of slowly opening up opportunities to other interested volunteers in areas where the appropriate criteria for success can be met.

**A word of caution. All of our volunteers need to understand that this effort is an experiment, and as such, we may need to call off the experiment if things don't go as we would otherwise like them to. For now, we begin with Step 1.**