LONG-TERM CARE TRANSITION

Most people wish to live in their own homes as long as they can. With increasing care needs, however, attempting to live at home can become extremely stressful and challenging, both for the person who is ill, as well as for family carers. The emotional and physical health of the entire family unit can be affected.

People with Huntington disease (HD) will eventually need professional support with their day-to-day living and care needs. As the disease progresses, this support and assistance goes beyond what can be provided in the home by either family or in-home health care providers.

Many family members affected by HD, including the person who has HD, often experience great relief and an improved quality of life once the move is made to long-term care (LTC). People are sometimes surprised by the degree of care and dedication provided by staff in such residences. Staff in long-term care facilities often form special bonds with people with HD, who are typically closer to them in age than the average resident. Staff are often keen to learn all they can about HD and how to make quality of life for people with HD the best it can be.

The Huntington Society of Canada's (HSC) Family Services team members are available to help with this education and to help develop the plan of care. To ease the transition into LTC, there are some important points to consider:

1. Be Proactive

Prepare early for LTC by discussing and planning for the future with the family. The discussions should happen well before the need to transition to LTC. Future planning includes identifying the Power of Attorney (for personal care and finances), wills and advance health care directives, education about LTC options in your community are all significant. It is important for family members to know the wishes of the person with HD; it provides peace of mind when the time comes for this move.

2. Build Your Team

At an HSC national conference Dr. Ed Wild, of the University College London Hospitals (UK), stated: "A large mountain is a large mountain - there is no magic solution but there are things you can do," (2010). He talked about the importance of building your own team of support formal and informal (friends/family and health professionals), planning ahead for the future, packing the right equipment (medications/assisted devices), sustaining hope and staying in charge of your journey. Stay in touch with your team as your needs change for emotional, spiritual and physical support now and for the future.

3. When is the "Right" Time?

Reaching out to health care professionals who regularly assess for such decisions can help ease the personal burden in decision-making. A knowledgeable third party can help a family review circumstances more objectively and provide facts that all can consider in making such a move. The professional may also be able to serve as a neutral mediator, should conflicts arise. Remember, there is also support available from the regional HD multidisciplinary team and your HSC social worker.

4. Funding Elibility

There are varying costs/fees for living in LTC. Each province in Canada has its own set of regulations around this, and the people assessing the needs for a care facility will explain them. Eligibility for subsidized funding also varies and is generally based on income. Please speak with your case manager or social worker to assess if the current situation meets eligibility criteria.

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5. Establishing a Familiar Environment

Sometimes, we have negative associations with LTC facilities or nursing homes. This is why it is important to visit a variety of homes to see how they operate today. Just because there may have been negative experiences in the past with family members, it does not mean that future experiences will be the same. Visit LTC options as a family. Meet with staff, take a tour, have a meal and get a sense of the environment. Discuss the pros and cons - as well as the wishes of the person with HD. You can take a checklist to help you with your questions.

6. Respite Services

To ease the transition to LTC, take advantage of respite hours. Most provinces fund a specific amount of respite hours per person per year; discuss with your case manager if respite is available at the facility you are considering.This experience gives everyone an opportunity to take a break from care, recharge their batteries and become familiar with the environment.

7. Prepare for the Emotional Impact

The transition to LTC can be an emotional and stressful time for all. Feelings of guilt when considering a care home and sadness over the change in the relationship can be part of the process. Grieving losses, talking through feelings - especially with those in similar situations (including attending support groups) - and accessing supportive counselling can be extremely beneficial during this process.

8. Family Continues to be Instrumental

When the person with HD moves into LTC there are many ways that you can still contribute by staying involved: Visit regularly; establish a point person who you will communicate with and know who to approach if questions or concerns arise; personalize the room with familiar furniture, photos and treasures. Encourage facility staff education, which HSC's Resource Centre Directors (RCDs) can provide to help them learn about HD and how to best support people affected by this illness. Create a Life/Memory Book - personal profiles and scrap books composed by the individual and family can help staff get to know residents with HD by highlighting a life well lived. They can also be used by staff as a future communication tool.

RESOURCES

Alzheimer Society of Canada | www.alzheimer.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: https://contactme.cloud/form/huntingtonsociety

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at www.huntingtonsociety.ca/family-services-team-list/

Informational fact sheets for family and friends impacted by HD are available to view, print and download at www.hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at www.huntingtonsociety.ca/hd-booklets-and-publications/

- A Physician's Guide to the Management of Huntington Disease
- Understanding Behaviour in Huntington Disease: A Guide for Professionals.
- A Carer's Guide for Huntington Disease

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