Home-Based Palliative End-of-Life Care in Newfoundland & Labrador
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Being cared for at home at the end of life

Many people facing the end of life would prefer dying in their own home rather than in a hospital. For this to happen, patients and their loved ones may need a form of care known as home-based palliative end-of-life care (HPC). HPC includes a team of health workers and home support workers who come to take care of patients and their loved ones as death draws near. The HPC team can give the patient medicine to help ease suffering. These health workers can help improve quality of life by providing relief and comfort, teaching and support. They can help people feel calmer and stay connected. They can help patients and their loved ones work through the experience of death in line with their own beliefs and they can even support families and loved ones in the grief that follows.

Why did we write this report?

Decision makers in Newfoundland and Labrador want to help people receive care in their own homes, including care at the end of life if this is what patients and their loved ones would prefer. With this idea in mind, health system decision makers from across the province asked us to find out more about HPC. They asked us to find out the following:

- Does HPC improve the chances of dying at home rather than in the hospital?
- Can HPC help to reduce pain and suffering for the patient?
- Can HPC improve the quality of life for patients and their loved ones?
- Will HPC provide relief to caregivers?
- Who should be included on the HPC team?
- What services should be offered to give the best quality HPC to patients and their loved ones?
How did we find the answers?

To answer these questions, we formed a project team that included experts in HPC, decision makers, patients, caregivers, and health workers with experience caring for people at the end of life. The team looked for the highest quality research we could find on HPC. We found six large review articles that combined and investigated a large number of research studies on the topic of HPC (these are called systematic reviews). We also found six good research studies that were finished too recently to be included in the review articles (these are called primary studies). We then combined the findings from all of this evidence and prepared a report to tell decision makers what the best research, taken together, has to say about HPC.

What did we find?

- When HPC is provided, patients are more likely to get their wish to die at home.
- HPC helps provide relief from pain and other symptoms.
- HPC teams that communicate well give patients a sense of security.
- The research was not so clear about other aspects of HPC, such as whether it improves quality of life or lowers the burden placed on caregivers—mostly because these things can be very hard to measure.
- The research was also unclear about what exactly is needed for HPC to work well. However, we did find some clues to these answers by looking at what kinds of workers and services were most often mentioned in the very best studies. All of the following health workers were mentioned: nurses, doctors, pharmacists, social workers, occupational therapists, physical therapists, and mental health professionals. The following services were also mentioned: teaching patients and caregivers how to manage their own care, providing mental health and social supports, treating the symptoms of an illness, providing support by telephone or online, and checking in on patients regularly.

How could the findings of this report work for us in Newfoundland and Labrador?

In addition to finding out what the research had to say about how HPC can work, we also asked people working in health and community settings across the province as well
as patients and caregivers to tell us how HPC might work in this province. The people we asked were able to tell us about factors that are unique to Newfoundland and Labrador—the local context. By placing the research in context, we came up with a list of things that decision makers may want to consider if they plan to provide high-quality HPC here in NL:

- Doctors, nurses and other health workers will need more training in HPC.
- The province will need more well-trained well-paid homecare workers who can help with personal care, especially outside larger cities.
- To work well, HPC requires enough government-funded homecare hours.
- Patients and their loved ones will need clear information about how to get HPC.
- Patients will need to be able to see doctors on evenings, weekends and on holidays.
- HPC will work better if there is good communication among different care providers working in different care settings.
- Affordable and convenient travel is important both for homecare workers and for patients.
- Health workers need to know more about the benefits of HPC. They need to be more comfortable talking about HPC with their patients. They also need to start having conversations not only at the end of life but also at earlier stages of a person’s illness.
- Care providers need to know that HPC can work for diseases other than cancer.
- If patients and families could apply for HPC on their own, without having to ask their doctor for a referral, more people might use HPC.
- In addition to HPC, hospice care can offer care in a home-like setting for people who are dying. Decision makers may wish to think about how to provide more hospice care homes across the province when the option of a death at home may not be available.