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FOR PEOPLE LIVING  
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DE CHANGEMENT POUR  
LES PERSONNES VIVANT  
AVEC LE VIH ET D'AUTRES  
INVALIDITÉS ÉPISODIQUES

# Introduction to Rehabilitation in the Context of HIV for Family Physicians

Prepared by *Realize*

(formerly the Canadian Working Group on HIV and Rehabilitation)  
for the College of Family Physicians of Canada  
2017



**Realize** (formerly Canadian Working Group on HIV and Rehabilitation [CWGHR]) is a national charitable organization working to improve the quality of life of people living with HIV and related conditions through rehabilitation research, education, and cross-sector partnerships. **Realize** members are individuals and organizations that have an interest in HIV, disability and rehabilitation. These include: community-based HIV/AIDS, disability and rehabilitation organizations; national professional associations and individual clinicians; unions; private-sector companies; people living with HIV and other disabilities; health care, social care and human resources professionals; and other people who are interested in HIV, disability and rehabilitation.

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# Introduction to Rehabilitation in the Context of HIV for Family Physicians

This educational module has been designed for The College of Family Physicians of Canada (CFPC) through an iterative process of consultation with the CFPC, content experts, primary care providers, and other stakeholders. As the gate-keepers to a variety of health and social services, family physicians have the capacity to increase access to rehabilitation services, and thus vastly improve quality of life for people living with human immunodeficiency virus (HIV), and HIV/Hepatitis C (HCV) co-infection.

## Key Messages:

- Rehabilitation is a key component of care, treatment and support for people living with HIV (PLWHIV).
- In the context of a chronic illness such as HIV, rehabilitation can improve quality of life, decrease the impact of the primary disease and/or secondary health issues (e.g. time lost), enhance functioning and coping, and support therapeutic adherence.<sup>1, 2, 3, 4, 5, 6</sup>
- When introduced early, rehabilitation may prepare people living with chronic disease to cope with episodes of illness and increase their symptom-free days<sup>4</sup> increasing their ability to engage in work and other productive activities more consistently.<sup>7</sup>
- Rehabilitation may decrease the need for pharmaceutical management of mental health issues and pain.<sup>8</sup>
- Family physicians play a critical role in educating patients living with HIV about available rehabilitation services that address their specific needs and providing referrals to these services.
- People with chronic illness who have access to rehabilitation services in the primary care setting are more satisfied with their care.<sup>9</sup>

This module will provide you with some basic information on the prevalence of HIV and HIV/HCV co-infection in Canada. It will also introduce some of the health-related challenges experienced by individuals living with these conditions. Next, the role of family physicians in HIV care and rehabilitation will be explored and you will be introduced to a variety of rehabilitation service providers with whom you may collaborate. Each of these providers is well-trained and positioned to meet one or more of the diverse needs of PLWHIV or HIV/HCV co-infection. Finally, several case studies will explore different kinds of rehabilitation relevant to these populations. Special attention will be paid to the recommended

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<sup>1</sup> Canadian Thoracic Society COPD Clinical Assembly. (2012): *Canadian Respiratory Guidelines: Pulmonary Rehabilitation Fact Sheet*. Accessed from [http://www.respiratoryguidelines.ca/sites/all/files/2012\\_CTS\\_Fact\\_Sheet\\_Pulmonary\\_Rehab.pdf](http://www.respiratoryguidelines.ca/sites/all/files/2012_CTS_Fact_Sheet_Pulmonary_Rehab.pdf)

<sup>2</sup> Canadian Physiotherapy Association. (2012). *The Value of Physiotherapy: Chronic Disease*. Accessed from [https://physiotherapy.ca/sites/default/files/valuePT/cpa\\_valuept\\_chronicdisease-en.pdf](https://physiotherapy.ca/sites/default/files/valuePT/cpa_valuept_chronicdisease-en.pdf)

<sup>3</sup> Hand, Law & McColl. (2011). Occupational therapy interventions for chronic diseases: a scoping review. *American Journal of Occupational Therapy*, 65(4), 428-436.

<sup>4</sup> Ravesloot, Seekins & White. (2005). Living Well with a Disability health promotion intervention: Improved health status for consumers and lower costs for health care policymakers. *Rehabilitation Psychology*, 50(3), 239-245.

<sup>5</sup> Scholten, Brodowicz, Graninger, Gardavsky, Pils, Pesau et al. (1999). Persistent functional and social benefit 5 years after a multidisciplinary arthritis training program. *Archives of Physical Medicine Rehabilitation*, 80, 1282-1287.

<sup>6</sup> Touchard & Berthelot. (1999). Collaborative home practice: Nursing and occupational therapy ensure appropriate medication administration. *Home Healthcare Nurse*, 17 (1), 45-51

<sup>7</sup> Roessler, Fitzgerald, Rumrill & Koch. (2001). Determinants of employment status among people with multiple sclerosis. *Rehabilitation Counselling Bulletin*, 45(1), 31-39.

<sup>8</sup> Rexe, K., McGibbon Lammi, B. & von Zweck, C. (2013). Occupational therapy: Cost-effective solutions for changing health system needs. *Healthcare Quarterly*. 16(1): 69-75. Accessed from <http://www.acotup-acpue.ca/PDFs/OT%20-%20Cost-Effective%20Solutions%20for%20Changing%20Health%20System%20Needs.pdf>

<sup>9</sup> Richardson, J. et al. (2010). Rehabilitation in a primary care setting for persons with chronic illness – a randomized controlled trial. *Primary Health Care Research & Development*, 11, 382-395.

actions family physicians can take to encourage awareness of and access to rehabilitation in the context of HIV.

## 1. Introduction: HIV in Canada

### Human Immunodeficiency Virus (HIV)

Based on the latest available estimates released by the Public Health Agency of Canada (PHAC) at the end of 2014, there were approximately 75 500 PLWHIV in Canada.<sup>10</sup> This population continues to grow as new infections are diagnosed and people live long-term with HIV thanks to combined antiretroviral therapies introduced almost 20 years ago.

The following provides a brief overview of prevalence of who is affected:

- 77.6% of PLWHIV in Canada are men and 22.4% are women.
- PHAC uses ‘exposure categories’ (e.g. men who have sex with men [MSM], heterosexual contact among people born in a country where HIV is endemic, heterosexual contact with a person at risk, etc.) to define sub-populations of PLWHIV based on how they came to be infected. The following exposure categories account for the majority of prevalent infections in Canada as of 2014
  - 49.3% of the total number of prevalent HIV infections are attributable to the MSM exposure category,
  - 31.3% to the heterosexual exposure categories, and
  - 15.3% to the injection drug use exposure category<sup>11</sup>.
- Indigenous communities are disproportionately impacted by HIV and have a prevalence rate 2.1 times higher than that of non-Aboriginal people in Canada (448/100 000 vs. 212/100 000). This disparity is related to the differential impact of the social determinants of health, including income, education, and housing, on Indigenous and non-Indigenous communities. Additionally, persistent racism and the consequences of residential schooling and colonialism have impacts across generations which, along with the determinants of health, can lead to increased vulnerability to infection among Indigenous persons.<sup>12</sup>

AIDS was first diagnosed in Canada in 1982. At that time, no one knew what caused the illness or how to treat it and as a result, many people died<sup>13</sup>. The lived experience of HIV has changed significantly since the early days of the epidemic. Today, consistent use of antiretroviral medications can halt the replication of the HIV virus and vastly slow disease progression.<sup>14</sup> Recent studies show that the life expectancy of many men living with HIV who have full access to treatment may approach that of their HIV-negative peers.<sup>15</sup> Unfortunately, the same doesn’t appear to be true for women, people of colour

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<sup>10</sup> Public Health Agency of Canada. (2014) Summary: Estimates of HIV Incidence, Prevalence and Proportion Undiagnosed in Canada, 2014. Accessed from <http://www.catie.ca/sites/default/files/2014-HIV-Estimates-in-Canada-EN.pdf>

<sup>11</sup> ibid

<sup>12</sup> Public Health Agency of Canada. (2014). HIV/AIDS Epi Updates Chapter 8: HIV/AIDS among Aboriginal People in Canada. Accessed from <http://www.catie.ca/sites/default/files/Chapter-8-Epi-Update-Aboriginal-people-in-Canada.pdf>

<sup>13</sup> Public Health Agency of Canada. (2007). A Brief History of HIV/AIDS in Canada. Accessed from <http://www.phac-aspc.gc.ca/aids-sida/info/1-eng.php>

<sup>14</sup> World Health Organization. (2015) Use of antiretrovirals for treatment and prevention of HIV infection. Accessed at <http://www.who.int/hiv/topics/treatment/en/>

<sup>15</sup> Samji, H. Cescon, A., Hogg, R.S., Modur, S.P., Althoff, K.N. Buchacz, K. et al. (2013). Closing the gap: Increases in life expectancy among treated HIV-positive individuals in the United States and Canada. PLoS ONE, 8(12): e81355. doi: 10.1371/journal.pone.0081355

or those who use drugs and live with HIV, and this is attributed to health inequities due to the social determinants of health in these populations. Stigma and discrimination continue to present significant challenges for many Canadians living with HIV.

HIV can now be described as a lifelong, chronic health condition. PLWHIV may experience episodic disability as a result of their illness.<sup>16,17</sup> Features that distinguish episodic disability include its unpredictability, and alternating periods of illness and wellness, both of which can have a negative impact on labour force participation, income security, access to care and services, scheduling and coordination of care, and social inclusion. Periods of illness and wellness may result from the condition itself, from common comorbidities, or from treatment.

Direct effects of HIV infection may include: isolation resulting from stigma/discrimination; flu-like symptoms sometimes associated with primary infection; fatigue; weight loss; fever; night sweats; and in more advanced HIV disease, opportunistic infections.<sup>18</sup>

In the era of the effective HIV treatment, it may seem like most people diagnosed with HIV in Canada today begin taking antiretroviral medication and thus minimize any AIDS-related illness disability that may be caused by the virus. However, recent studies show that we have a long way to go to meet UNAIDS treatment targets.<sup>19,20</sup> UNAIDS developed the 90-90-90 treatment cascade as a strategy to end HIV/AIDS by 2020. These targets aim to have 90% of people at risk of HIV know their status, 90% of people who are HIV+ receive antiretroviral treatment, and 90% of people receiving treatment achieve an undetectable viral load. Globally, this strategy is being adopted by governments as part of their HIV/AIDS strategies. In 2015, the Public Health Agency of Canada also adopted these targets as the focus of their national response to HIV, but even so:

- In 2011, 71% of PLWHIV in British Columbia had been diagnosed, 51% were on treatment, and 35% had undetectable viral loads.<sup>21</sup>
- In 2015, 81% of PLWHIV in Ontario had been diagnosed, 66% were on treatment, and 62% had undetectable viral loads.<sup>22</sup>
- According to the Public Health Agency of Canada, about 21% of PLWHIV in Canada are unaware of their infection and therefore remain untreated.<sup>23</sup>

One Canadian study showed that the people most likely to be diagnosed with HIV at a more advanced stage of the disease (1996-2008) were those who; were perceived as lower risk (older adults;

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<sup>16</sup> Deeks, S., Lewin, S., & Havlir, D. (2013). The end of AIDS: HIV infection as a chronic disease. *The Lancet*. 382: 1525-33

<sup>17</sup> Realize. (n.d.) What is an Episodic Disability? Accessed from <http://www.realizecanada.org/en/our-work/episodic-disabilities/what-is-episodic-disability/>

<sup>18</sup> Thaczuk, D. (2011). A Practical Guide to HIV Drug Treatment for PLWHIV. 2<sup>nd</sup> ed. CATIE (Canadian AIDS Treatment Information Exchange). Accessed from <http://www.catie.ca/en/practical-guides/hiv-drug-treatment/2-hiv-and-aids-basics/2-2>

<sup>19</sup> amfAR. (2013). The HIV Treatment Cascade. The GMT Initiative. Accessed from [http://www.amfar.org/uploadedFiles/amfar.org/Around\\_the\\_World/MSM%281%29/GMT%20HIV%20Treat%20Cascade%20120213.pdf](http://www.amfar.org/uploadedFiles/amfar.org/Around_the_World/MSM%281%29/GMT%20HIV%20Treat%20Cascade%20120213.pdf)

<sup>20</sup> Rogers, T. (2015). Changing the Narrative: Why HIV Prevention Work in Canada Needs to Embrace HIV Treatment. CATIE: Canada's source for HIV and hepatitis C information. Accessed from <http://www.catie.ca/en/printpdf/pif/spring-2015/changing-narrative-why-hiv-prevention-work-canada-needs-embrace-hiv-treatment>

<sup>21</sup> Nosyk, B., Montaner, J., Colley, G., Lima, V., Chan, K., & Heath, K. et al. (2014). The cascade of HIV care in British Columbia, Canada, 1996–2011: A population-based retrospective cohort study. *The Lancet Infectious Diseases*, 14(1), 40-49. [http://dx.doi.org/10.1016/s1473-3099\(13\)70254-8](http://dx.doi.org/10.1016/s1473-3099(13)70254-8)

<sup>22</sup> Ontario Advisory Committee on HIV/AIDS. (2017). HIV/AIDS Strategy to 2026: Focusing our efforts - Changing the course of the HIV prevention, engagement and care cascade in Ontario. Toronto: Ministry of Health and Long-Term Care. Retrieved from [http://www.health.gov.on.ca/en/pro/programs/hivaids/docs/oach\\_strategy\\_2026.pdf](http://www.health.gov.on.ca/en/pro/programs/hivaids/docs/oach_strategy_2026.pdf)

<sup>23</sup> Public Health Agency of Canada. (2014) Summary: Estimates of HIV Incidence, Prevalence and Proportion Undiagnosed in Canada, 2014. Accessed from <http://www.catie.ca/sites/default/files/2014-HIV-Estimates-in-Canada-EN.pdf>

heterosexual persons with no other identified risks; those never previously tested for HIV and; people with no history of an HIV-positive partner).<sup>24</sup>

In addition to the effects of under-treated HIV, there are also several diseases which are more prevalent among HIV-positive individuals as compared to those who are not living with HIV, including mental health issues, chronic obstructive pulmonary disease, asthma, diabetes and stroke.<sup>25</sup> In addition, PLWHIV have been found to have a higher risk of frailty,<sup>26</sup> cancers (anal, liver, cervical, and Hodgkin's lymphoma)<sup>27,28</sup> and kidney disease.<sup>29</sup> Each of these comorbidities comes with its own set of related symptoms which may interfere with a person's capacity or activities.

Neurocognitive issues, most often mild but not in all cases, also impact PLWHIV, though it is emerging that differences in cognitive function between HIV+ and HIV- populations may be less pronounced than previously thought.<sup>30</sup> One study found that women living with HIV processed information more slowly, engaged in poorer quality decision-making and had diminished executive functioning than a closely matched HIV-negative control group, as measured by a battery of cognitive tests.<sup>31</sup> The authors noted that differences found between the HIV-positive and HIV-negative groups in their study were less marked than in studies which compare the test results of PLWHIV with normative data, however.

The same study found that poorer neurocognitive function among women living with HIV was associated with having a detectable viral load, depressive symptoms, and active HCV infection. Other studies also associate these factors, as well as low CD4 nadir, with poorer neurocognitive performance in other populations living with HIV.<sup>32,33,34</sup> There remains some disagreement about how substance use history impacts neurocognitive function among PLWHIV.<sup>35,36,37</sup>

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<sup>24</sup> Rank, C., Lloyd-Smith, E. & Gilbert, M. (2011). Advanced HIV Disease at the Time of Diagnosis in British Columbia. Accessed at [http://www.bccdc.ca/NR/rdonlyres/332498AE-1B79-4D29-8F3D-AD9034D1576F/0/STI\\_HIVSpecialReport\\_20110401.pdf](http://www.bccdc.ca/NR/rdonlyres/332498AE-1B79-4D29-8F3D-AD9034D1576F/0/STI_HIVSpecialReport_20110401.pdf)

<sup>25</sup> Kendall, C.E. et al. (2014). A cross-sectional, population-based study measuring comorbidity among PLWHIV in Ontario. BMC Public Health, 14: 161. Accessed from <http://www.biomedcentral.com/content/pdf/1471-2458-14-161.pdf>

<sup>26</sup> Desquilbet, Jacobson, Fried, Phair, Jamieson, Holloway, Margolick, Multicenter AIDS Cohort Study (2007). HIV-1 Infection is associated with an earlier occurrence of a phenotype related to frailty. J Gerontol A Biol Sci Med Sci, 62(11): 1279-86. Accessed from <https://doi.org/10.1093/gerona/62.11.1279>

<sup>27</sup> Abraham, A.G. et al. (2013). Invasive cervical cancer risk among HIV-infected women: A North American multi-cohort collaboration prospective study. J Acquir Immune Defic Syndr., 62(4), 405-413. [http://journals.lww.com/jaids/fulltext/2013/04010/Invasive\\_Cervical\\_Cancer\\_Risk\\_Among\\_HIV\\_Infected.6.aspx](http://journals.lww.com/jaids/fulltext/2013/04010/Invasive_Cervical_Cancer_Risk_Among_HIV_Infected.6.aspx)

<sup>28</sup> Pinzone, M.R. et al. (2012). Non-AIDS-defining cancers among HIV-infected people. European Review for Medical and Pharmacological Sciences, 16, 1377-1388. <http://www.europeanreview.org/wp/wp-content/uploads/1377-1388.pdf>

<sup>29</sup> Islam, F.M., Wu, J., Jansson, J. and Wilson, D.P. (2012). Relative risk of renal disease among PLWHIV: a systematic review and meta-analysis. BMC Public Health, 12:234. <http://www.biomedcentral.com/1471-2458/12/234/>

<sup>30</sup> McDonnell, J., Haddow, L., Daskalopoulou, M., Lampe, F., Speakman, A., Gilson, R et al. (2014). Minimal cognitive impairment in UK HIV-positive men who have sex with men: effect of care definitions and comparison with the general population and HIV-negative men. J Acquir Immune Defic Syndr, 67(2), 120-127.

<sup>31</sup> Giesbrecht, C.J., Thornton, A.E., Hall-Patch, C., Maan, E.J., Côté, H.C.F., Money, D.M. et al. (2014). Select neurocognitive impairment in HIV-infected women: Associations with HIV viral load, hepatitis C virus, and depression, but not leukocyte telomere length. PLoS One, 9(3), e89556.

<sup>32</sup> Haddow, L.J., Cartledge, J.D., Manji, H. (2013). HIV and the brain: From AIDS to old age. Clinical Medicine, 13(6), s24-s28.

<sup>33</sup> Heaton, R.K., Clifford, D.B., Franklin, D.R., Woods, S.P., Ake, C. et al. (2010). HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy. Neurology, 75(3), 2087-2096.

<sup>34</sup> Ellis, R.J., Badiee, J., Vaida, F., Letendre, S., Heaton, R.K. et al. (2011). CD4 nadir is a predictor of HIV neurocognitive impairment in the era of combination antiretroviral therapy. AIDS, 25(14). doi: [10.1097/QAD.0b013e32834a40cc](https://doi.org/10.1097/QAD.0b013e32834a40cc)

<sup>35</sup> Devlin, K.N., Gongvatana, A., Clark, U.S., Chasman, J.D., Westbrook, M.L. et al (2012). Neurocognitive effects of HIV, hepatitis C, and substance use history. J Int Neuropsychol Soc, 18(1), 68-78.

<sup>36</sup> Weber, E., Morgan, E.E., Iudicello, J.E., Blackstone, K., Grant, I. et al. (2012). Substance use is a risk factor for neurocognitive deficits and neuropsychiatric distress in acute and early HIV infection. Journal of Neurovirology, 19(1), 65-74.

<sup>37</sup> Byrd, D.A., Fellows, R.P., Morgello, S., Franklin, D., Heaton, R.K., Deutsch, R. et al. (2011). Neurocognitive impact of substance use in HIV infection. J Acquir Immune Defic Syndr, 58, 154-162.

Finally, combination antiretroviral treatment (cART), though much improved since its introduction in 1996, may also have side effects. Some of these adverse reactions tend to be short term, but may persist or recur, including weakness, headaches, diarrhea, nausea, flatulence, rash, drowsiness, insomnia, vivid dreams, depression, confusion, and impaired concentration. Long-term negative effects, such as decreased bone mineral density, hyperglycemia, hyperlipidemia, lipodystrophy and renal insufficiency contribute to the development of the comorbidities previously mentioned.<sup>38</sup> In a recent study, more than 25% of PLWHIV reported new distal neuropathic pain over a two year period and being on cART was a predictor of pain development.<sup>39</sup> Treatment can thus contribute to interruptions in the lives of PLWHIV in Canada.

No two PLWHIV experience the virus, cART, comorbidities or social determinants of health in exactly the same way. While some people experience a multitude of symptoms and side effects, others feel mostly well day-to-day. There is no 'typical' PLWHIV so it is very important to take a patient-centered approach to care. Being actively involved in making treatment decisions has been deemed one of the most important factors contributing to satisfaction with care among PLWHIV.<sup>40</sup> Satisfaction with care appears to contribute to both patient retention and cART adherence.<sup>41</sup>

Competing life choices and lack of access to needed medications are two other barriers to cART adherence and treatment success. Several systematic reviews have been published, reviewing the literature on adherence as it relates to special populations (e.g. women, youth), patients with specific characteristics (e.g. aging with comorbidities, role of employment) and different treatment strategies (e.g. single dose versus multiple doses, text reminders). While there is limited high quality evidence to identify interventions that best improve adherence, Enriquez and McKinsey<sup>42</sup> provide a narrative review of the literature in this area. In addition to summarizing barriers and facilitators of antiretroviral therapy adherence, they also list recommendations for clinicians to consider or try that they themselves have used with some success.

## HIV/Hepatitis C Coinfection

Approximately 20-30% of PLWHIV are also co-infected with Hepatitis C (HCV).<sup>43</sup> People who use injection drugs are the most likely population to be coinfecting with HIV and HCV, and their care is often complicated by the fact that they may be under-housed, living in poverty, isolated, or highly stigmatized.<sup>44</sup> This is especially problematic as co-infection can facilitate rapid progression of HCV<sup>45</sup> and

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<sup>38</sup> Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Appendix B: Drug Characteristics Tables (P-1). Department of Health and Human Services. Accessed from <http://aidsinfo.nih.gov/contentfiles/vguidelines/adultandadolescentgl.pdf>

<sup>39</sup> Malvar, J., Vaida, F., Sanders, C.F., Atkinson, J.H., Bohannon, W., Keltner, J. et al. (2015). Predictors of new onset distal neuropathic pain in the HIV-infected individuals in the era of combination antiretroviral therapy. *Pain*, Accessed from [http://journals.lww.com/pain/Abstract/publishahead/Predictors\\_of\\_New\\_Onset\\_Distal\\_Neuropathic\\_Pain\\_in.99931.aspx](http://journals.lww.com/pain/Abstract/publishahead/Predictors_of_New_Onset_Distal_Neuropathic_Pain_in.99931.aspx)

<sup>40</sup> Tsisis, P., Tsoukas, C., Deutsch, G. (2000). Evaluation of patient satisfaction in a specialized HIV/AIDS care unit of a major hospital. *AIDS Patient Care and STDs*, 14(7), 347-349.

<sup>41</sup> Dang, B.N., Westbrook, R.A., Black, W.C., Rodriguez-Barradas, M.C., Giordano, T.P. (2013). Examining the link between patient satisfaction and adherence to HIV care: a structural equation model. *PLoS One*, 8(10), e54729.

<sup>42</sup> Enriquez M, McKinsey DS. Strategies to improve HIV treatment adherence in developed countries: clinical management at the individual level. *HIV AIDS (Auckl)*. 2011;3:45-51. doi: 10.2147/HIV.S8993. Epub 2011 May 17. PubMed PMID: 22096406; PubMed Central PMCID: PMC3218706.

<sup>43</sup> Hull, M., Shafran, S., Wong, A., Tseng, A., Giguère, P., et al. (2016). CIHR Canadian HIV trials network co-infection and concurrent diseases core research group: 2016 Updated Canadian HIV/Hepatitis C adult guidelines for management and treatment. *Canadian Journal of Infectious Diseases and Medical Microbiology*. <http://dx.doi.org/10.1155/2016/4385643>

<sup>44</sup> Grebely, J., Oser, M., Taylor, L.E. & Dore, G.J. (2013). Breaking down the barriers to hepatitis C virus (HCV) treatment among individuals with HCV/HIV coinfection: action required at the system, provider, and patient levels. *J Infect Dis*, 207 (Suppl 1), s19-s25.



result in debilitating symptomatology and increased morbidity and mortality.<sup>46</sup> In 2016, the World Health Organization updated their Guidelines for the screening care and treatment of persons with chronic hepatitis C infection. It is now recommended to treat PLWHCV with oral direct-acting antiviral agents to cure the infection. These antiviral agents require a shorter duration of treatment and have a greater than 90% success rate in curing the infection.<sup>47</sup> This recommendation is also indicated in people living with HIV/HCV co-infection as an effective and well-tolerated treatment option. The advent of these oral direct-acting antiviral agents should reduce the need to manage HIV/HCV co-infection.<sup>48</sup>

## 2. The Role of the Family Physician in HIV Prevention, Screening and Treatment

Family physicians play a critical role in HIV prevention in Canada. They are a first point of contact in the healthcare system and a trusted source of information for many of their patients. Even so, initiating conversations about sexual and reproductive health can be difficult and many family doctors avoid it.

In one study of almost 750 General Practitioners in Quebec, less than half of clinicians asked about condom use, number of sexual partners, sexually transmitted infection status of partner(s), or sex of partner(s) when providing care to adults.<sup>49</sup> Not having these discussions is a missed opportunity for sharing HIV prevention information and encouraging screening among individuals who may be vulnerable to HIV. Prompt diagnosis and treatment initiation is the first line of defense against HIV-related health complications.<sup>50</sup>

According to the Public Health Agency of Canada, HIV testing is clinically indicated and should be done routinely in the following circumstances:

- An individual has symptoms and signs of HIV infection;
- An individual has an illness associated with a weakened immune system;
- An individual is diagnosed with tuberculosis (active or latent infection);
- A woman is pregnant or planning a pregnancy; and partner(s) as appropriate.<sup>51</sup>

HIV testing should be offered/provided to an individual who:

- Has an identified risk factor for HIV infection or is at risk for other STIs;
- Requests an HIV test;
- Is sexually active but has not been tested for HIV;
- Reports unprotected anal or vaginal intercourse or the use of shared drug equipment with

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<sup>45</sup> CATIE. (2013). Living with HIV and Hepatitis C Co-infection. Accessed from <http://www.catie.ca/sites/default/files/co-infection-en-2013.pdf>

<sup>46</sup> Hull, M., Shafraan, S., Wong, A., Tseng, A., Giguère, P., et al. (2016). CIHR Canadian HIV trials network co-infection and concurrent diseases core research group: 2016 Updated Canadian HIV/Hepatitis C adult guidelines for management and treatment. *Canadian Journal of Infectious Diseases and Medical Microbiology*. <http://dx.doi.org/10.1155/2016/4385643>

<sup>47</sup> World Health Organization. (2016). Guidelines for the screening care and treatment of persons with chronic hepatitis C infection. Updated version, April 2016. Geneva: World Health Organization. Retrieved from [http://apps.who.int/iris/bitstream/10665/205035/1/9789241549615\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/205035/1/9789241549615_eng.pdf?ua=1)

<sup>48</sup> Hull, M., Shafraan, S., Wong, A., Tseng, A., Giguère, P., & Barrett, L. et al. (2016). CIHR Canadian HIV Trials Network Coinfection and Concurrent Diseases Core Research Group: 2016 Updated Canadian HIV/Hepatitis C Adult Guidelines for Management and Treatment. *Canadian Journal Of Infectious Diseases And Medical Microbiology*, 2016, 1-34. <http://dx.doi.org/10.1155/2016/4385643>

<sup>49</sup> Haley, N., Maheux, B., Rivard, M., Gervais, A. (1999). Sexual health risk assessment and counseling in primary care: How involved are general practitioners and Obstetrician/Gynecologists? *American Journal of Public Health*, 89(6), 899-902.

<sup>50</sup> Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services. Available at <http://aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. Initiating Antiretroviral Therapy in Treatment-Naïve Patients.

<sup>51</sup> PHAC. (2017). Canadian Guidelines on Sexually Transmitted Infections: 2016 Updates Summary. Ottawa: Her Majesty the Queen in Right of Canada, as represented by the Minister of Health, 2017. Retrieved from <http://www.phac-aspc.gc.ca/std-mts/sti-its/assets/pdf/updates-summary-eng.pdf>

- A partner whose HIV status is positive or unknown;
- Is a victim of sexual assault.<sup>52</sup>

Requesting an HIV test from a family physician can leave a person feeling vulnerable because they may be asked to share information about their behaviour to justify the need for screening. After diagnosis, people living with HIV, may continue to feel vulnerable when seeking support. Even though the HIV epidemic is more than 30 years old, health care provider stigma is still present in various settings, including primary care, which creates a barrier to accessing care for PLWHIV.<sup>53</sup> It is important to note that HIV-related stigma often intersects with other forms of stigma including race, culture and ethnicity, and sexual orientation.<sup>54</sup>

Providers of family medicine should take stock of their own values and beliefs about HIV and consider how these may impact their patient interactions since it is family physicians who provide the bulk of the care for people living with HIV (PLWHIV) in Canada. According to a recent study, 3699 family doctors provided 78% of all care for PLWHIV in Ontario between 2009 and 2012.<sup>55</sup> One in three Ontario family doctors is monitoring the health of at least one HIV-positive person. Below, we share more of the information published in this study by Kendall and colleagues.

In Ontario, the majority of family doctors working with PLWHIV have only a few ( $\leq 5$ ) patients living with HIV on their roster, and approximately 21% work with between 6 and 49 patients living with HIV. Only a small percentage of the care physicians in these two groups provide to PLWHIV is HIV-related. Still, these physicians make significant contributions to the overall health of their HIV-positive patients.

As PLWHIV live longer, their health issues may become more complex. As previously described, comorbidity- and aging-related impairments may be experienced in addition to the direct effects of HIV and its treatments. Family physicians are optimally suited to help prevent, detect, and manage the chronic conditions that are prevalent among PLWHIV (such as heart disease, diabetes, chronic pain, mental health issues, frailty, osteoporosis and cancer) as these are health issues they address often in general practice now that the overall Canadian population is aging.

About 2% of family physicians in Ontario provide care to more than 50 PLWHIV each. For these practitioners, HIV-related visits, which may include regular monitoring of CD4 cell counts and plasma viral loads, addressing barriers to antiretroviral adherence, and addressing complications of antiretroviral therapy<sup>56</sup>, represent almost 70% of all appointments with PLWHIV.

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<sup>52</sup> PHAC. (2017). Canadian Guidelines on Sexually Transmitted Infections: 2016 Updates Summary. Ottawa: Her Majesty the Queen in Right of Canada, as represented by the Minister of Health, 2017. Retrieved from <http://www.phac-aspc.gc.ca/std-mts/sti-its/assets/pdf/updates-summary-eng.pdf>

<sup>53</sup> Wagner, A.C., McSha

ne, K.E., Hart, T.A. & Margolese, S. (2016). A focus group qualitative study of HIV stigma in the Canadian healthcare system. *The Canadian Journal of Human Sexuality*, 25(1): 61-71. doi:10.3138/cjhs.251-A6

<sup>54</sup> Mill, J., Edwards, N., Jackson, R., Austin, W., MacLean, L., & Reintjes, F. (2009). Accessing health services while living with HIV: Intersections of stigma. *Canadian Journal of Nursing Research*, 41(3), 168-185.

<sup>55</sup> Kendall, C.E., Wong, J., Maljaard, M., Glazier, R.H., Hogg, W., Younger, J., Manuel, D.G. (2015). A cross-sectional, population-based study of HIV physicians and outpatient health care use by people with HIV in Ontario. *BMC Health Services Research*, 15:63.

<sup>56</sup> British Columbia Centre for Excellence in HIV/AIDS. (2015). Primary Care Guidelines for the Management of HIV/AIDS in British Columbia. Accessed from [http://www.cfenet.ubc.ca/sites/default/files/uploads/primary-care-guidelines/primary-care-guidelines\\_015-09-15.pdf](http://www.cfenet.ubc.ca/sites/default/files/uploads/primary-care-guidelines/primary-care-guidelines_015-09-15.pdf)

### 3. Disability among PLWHIV or HIV/HCV Co-Infection

Individuals living with HIV or HIV/HCV co-infection may experience physical, mental, social, and/or emotional health-related challenges attributed to their illness, its associated conditions, or antiretroviral treatments, a concept that may be called disability. **Disability** is defined by the World Health Organization as impairments, activity limitations, and participation restrictions experienced by an individual (see textbox below).<sup>57</sup>

The World Health Organization's model, the International Classification of Functioning, Disability and Health (ICF), categorizes health-related experiences beyond those covered by the concept of disease. The model lays out three categories, from the micro level (body part, individual) to the macro level (community or society):

- **Impairments:** Impairments are problems in body function or structure; they are at the level of the body part, structure or function. E.g.: pain or tingling in feet secondary to peripheral neuropathy.
- **Activity Limitations:** These are difficulties an individual may have executing activities; they are at the level of the person. E.g.: difficulties walking because of pain and sensitivity in feet.
- **Participation Restrictions:** These are problems an individual may experience in life situations or the social and environmental consequences of impairments and activity limitations; they are at the level of community or society. E.g.: difficulties working or taking care of children.

Rehabilitation interventions may be targeted at one or more level in the ICF.

For more information about ICF, go to [Towards a Common Language for Functioning, Disability and Health: ICF](#)

### 4. Rehabilitation in the Context of HIV and HIV/HCV Co-Infection

**Rehabilitation** can be broadly defined as any services that address or prevent impairments, activity limitations and social participation restrictions experienced by people living with HIV (PLWHIV) or other chronic and episodic illnesses.<sup>58</sup> Optimizing choices by providing the tools and support to help people do what is meaningful to them, including physical, cognitive, vocational, and psychological rehabilitation interventions, is essential. One of the French translations for rehabilitation, *réinsertion sociale* or, literally translated, "social re-insertion" captures a fundamental aspect of the rehabilitation process: return to active living and participation in society.

Three primary goals of rehabilitation are:<sup>59</sup>

- To increase or maintain functional capacity
- To improve or maintain a person's quality of life, and
- To decrease hospitalizations and increase self-care

<sup>57</sup> World Health Organization. (n.d.) *Disabilities*. Accessed from [www.who.int/topics/disabilities/en/](http://www.who.int/topics/disabilities/en/)

<sup>58</sup> Worthington C, Myers T, O'Brien K, Nixon S, Cockerill R: Rehabilitation in HIV/AIDS: development of an expanded conceptual framework. *AIDS Patient Care STDS* 2005, 19(4):258-271

<sup>59</sup> Realize. (2017). *E-module for Evidence-Informed HIV Rehabilitation*. Accessed from [http://www.realizecanada.org/wp-content/uploads/E-Module\\_2017\\_24mar.pdf](http://www.realizecanada.org/wp-content/uploads/E-Module_2017_24mar.pdf)

Within these goals, rehabilitation can include a range of services, programs and policies that seek to:

- Address impairments, activity limitations and participation restrictions related to HIV, comorbid health conditions, aging, or the side effects of medications, including managing pain, weakness or fatigue and increasing mobility and independence;
- Offer non-pharmacologic coping strategies to help manage treatment side effects, promote medication adherence and support the integration of often complex treatment regimens into daily activities, with the ultimate goal of lowering viral load, reducing drug resistance and preventing drug interactions;
- Enhance a person's ability to stay at or return to employment or volunteer work;
- Improve access to adequate income supports which enable individuals to focus on improving their health and participation in society;
- Build self-esteem, maintain interpersonal relationships and support networks and reduce stress and isolation.

Many health care providers, including physicians, nurses and dieticians have been working in rehabilitation with PLWHIV since the beginning of the epidemic; however, developments in the medical management of HIV have changed the role and scope of rehabilitation.

Rehabilitation in this context now involves many players, including health care professionals who have not traditionally been involved in HIV issues, such as physiotherapists, occupational therapists, speech-language pathologists, and psychiatrists. Many rehabilitation services are also provided by other practitioners, including: vocational counsellors, case managers, complementary therapists, social workers, frontline and peer workers in community-based health and social service organizations, addictions counsellors, and personal support workers.

Community-based HIV organizations (CBHOs) are important providers of rehabilitation services and supports for PLWHIV. These organizations provide safe spaces in which PLWHIV can talk openly about their health status, give and receive support from peers, and build their capacity to cope with their illness. Programs offered by CBHOs include: peer support groups, workshops, counselling, practical assistance (accompaniment to appointments, food banks, etc.), and social activities. In large urban centres, PLWHIV may be able to access CBHOs that offer services geared toward their cultural or gender-specific needs. A broad range of HIV services offered across Canada can be located using [HIV/HCV 411](#).

## **5. The Role of Family Physicians in Access to Rehabilitation for PLWHIV**

Family physicians play a critical role in ensuring access to rehabilitation for their patients. Doctors providing primary care to PLWHIV often act as gatekeepers to rehabilitation services and are thus encouraged to:

- Educate patients about rehabilitation services that may be helpful in addressing their specific health challenges or disability;
- Ensure each of your patients has access to a health system navigator, case manager, social worker or case worker who can help them find no- or low-cost rehabilitation services available in

their community. If they can't access this type of support through your practice, refer them to a local community-based HIV organization. You can locate one nearby using [HIV/HCV 411](#)

- Provide referrals so patients can access institutional and community-based rehabilitation service providers, as appropriate
- Ask patients about the full range of rehabilitation services they are accessing (including self-care strategies) so these services can be better integrated into the patient's treatment plan
- Maintain open communication with rehabilitation providers when consultation is requested by the patient
- Clearly specify the need for rehabilitation services in communication with insurance and/or benefits providers

Evidence suggests that rehabilitation interventions may be used to reduce the risk of adverse events (e.g. falls),<sup>60</sup> lessen symptom burden,<sup>61</sup> increase social support,<sup>62</sup> and build resiliency<sup>63</sup> among PLWHIV and are therefore complementary to the care provided by the physician. Multidisciplinary approaches to care have also been shown to maximize the amount of time physicians spend providing care that is matched to their level of expertise.<sup>64</sup>

## 6. Relevant Topics in Rehabilitation

### a. Rehabilitation as Prevention

People living with HIV (PLWHIV) tend to live with more comorbidities than their HIV-negative peers<sup>65</sup> therefore interventions designed to prevent or postpone disease progression are important, especially for older adults. Rehabilitation interventions, like those provided in exercise-based cardiac rehabilitation programs, may help reduce the harms associated with serious HIV-related comorbidities.<sup>66</sup> Addressing medication side effects using rehabilitation, through mindfulness based stress reduction for example, may also serve to promote adherence to cART, thereby preventing HIV disease progression and contributing to enhanced potential for sustained virological response.<sup>67</sup>

With regard to rehabilitation as prevention, family physicians treating PLWHIV should:

- Make appropriate referrals to rehabilitation professionals when early stages of physical, cognitive or functional decline are observed

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<sup>60</sup> O'Brien, K.K., Solomon, R., Trentham, B., MacLachlan, D., MacDermid, J., Tynan, A-M. et al. (2014). Evidence-informed recommendations for rehabilitation with older adults living with HIV: a knowledge synthesis. *BMJ Open*, 4:e004692 doi:10.1136/bmjopen-2013-004692.

<sup>61</sup> Duncan, L.G., Moskowitz, J.T., Neilands, T.B., Dilworth, S.E., Hecht, F.M, Johnson, M.O. (2012). Mindfulness-based stress reduction for HIV treatment side effects: a randomized, wait-list controlled trial. *Journal of Pain and Symptom Management*, 43 (2), 161-171.

<sup>62</sup> Bekele, T., Rourke, S.B., Tucker, R, Greene, S., Sobota, M, Koornstra, J et al. (2013). Direct and indirect effects of perceived social support on health-related quality of life in persons living with HIV/AIDS. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 25(3).

<sup>63</sup> Harper, G.W., Bruce, D., Hosek, S.G., Fernandez, M.I., Rood, B.A. and the Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2014). Resilience processes demonstrated by young gay and bisexual men living with HIV: Implications for intervention. *AIDS Patient Care and STDs*, 28 (12).

<sup>64</sup> Hupke, C. (2014). Team-Based Care: Optimizing Primary Care for Patients and Providers. Institute for Healthcare Improvement. Accessed from [http://www.ihc.org/communities/blogs/\\_layouts/ihc/community/blog/itemview.aspx?List=0f316db6-7f8a-430f-a63a-ed7602d1366a&ID=29](http://www.ihc.org/communities/blogs/_layouts/ihc/community/blog/itemview.aspx?List=0f316db6-7f8a-430f-a63a-ed7602d1366a&ID=29)

<sup>65</sup> Kendall, C.E., Wong, J., Taljaard, M., Glazier, R.H., Hogg, W., Younger, J & Manuel, D.G. (2014). A cross-sectional, population-based study measuring comorbidity among PLWHIV in Ontario. *BMC Public Health*, 14:161.

<sup>66</sup> O'Brien, K.K., Solomon, P., Trentham, B., MacLachlan, D., MacDermid, J. & Tynan, A-M. (2014). Evidence-informed recommendations for rehabilitation with older adults living with HIV: A knowledge synthesis. *BMJ Open*: 4:e004692. doi:10.1136/bmjopen-2013-004692

<sup>67</sup> Duncan, L.G., Moskowitz, J.T., Neilands, T.B., Dilworth, S.E., Hecht, F.M, Johnson, M.O. (2012). Mindfulness-based stress reduction for HIV treatment side effects: a randomized, wait-list controlled trial. *Journal of Pain and Symptom Management*, 43 (2), 161-171.

- Make referrals to rehabilitation professionals for preventative rehabilitation when the patient is also diagnosed with a condition that is known to result in physical, cognitive or functional declines

## **b. Stigma**

PLWHIV or HIV/HCV co-infection often face intersecting forms of discrimination when attempting to access health services, including stigma based on real or perceived HIV/HCV status, gender and/or sexual identity, race/ethnicity, engagement in sex work, homelessness/poverty, mental illness, drug use, or history of incarceration. It is important that referrals be made to rehabilitation service providers who are knowledgeable about the experiences of PLWHIV and who will create safe environments for them.

Stigmatization and the need for confidentiality continue to present challenges for PLWHIV. If the need for consultation between a family physician and a rehabilitation provider arises, it is important that the patient is given the opportunity to express his/her explicit consent prior to any disclosure of medical status. As the Canadian HIV/AIDS Legal Network writes, *“there is currently no legislation or case law obliging patients to tell their doctors, nurses, dentists, surgeons, paramedics or any other health professionals that they are HIV-positive.”*<sup>68</sup>

For more information about stigma and some strategies to combat individual, environmental and policy related stigma refer to the following documents:

- [Combating HIV stigma in health care settings: What works?](#) by Nyblade et al<sup>69</sup>
- [Achieving a Stigma-Free Health Facility and HIV Services](#) by Carr, Kidd, Fitzgerald & Nyblade<sup>70</sup>

With regard to stigma, family physicians treating PLWHIV should:

- Allow the patient the opportunity to express his/her explicit consent prior to any disclosure of medical status
- Create a code of conduct that guides staff to create and maintain a stigma-free services
- Ensure that at the individual level, all staff are educated on what stigma is and their fears and misconceptions related to HIV are addressed

## **c. Access to Rehabilitation**

Access to rehabilitation services across Canada is impacted by various factors including location, diagnosis, cost and waitlists. A recent environmental scan of publically-funded rehabilitation services across Canada found that in urban settings and large cities, a greater number of publically-funded rehabilitation services, and greater variety and scope of rehabilitation services were available.<sup>71</sup> Inconsistency in terms of the distribution of publicly-funded services between communities of varying size, and among provinces and territories impacts equitable access to affordable rehabilitation services for PLWHIV.

<sup>68</sup> Canadian HIV/AIDS Legal Network. (2014). Living with HIV – Know Your Rights: Disclosure as a Patient. Accessed from [http://www.aidslaw.ca/site/wp-content/uploads/2014/06/KYR\\_5\\_E\\_web.pdf](http://www.aidslaw.ca/site/wp-content/uploads/2014/06/KYR_5_E_web.pdf)

<sup>69</sup> Nyblade, L., Stangl, A., Weiss, E., & Ashburn, K. (2009). Combating HIV stigma in health care settings: What works?. *Journal Of The International AIDS Society*, 12(1), 15. <http://dx.doi.org/10.1186/1758-2652-12-15>

<sup>70</sup> Carr, D., R. Kidd, M. Fitzgerald, and L. Nyblade. 2015. *Achieving a Stigma-free Health Facility and HIV Services: Resources for Administrators*. Washington, DC: Futures Group, Health Policy Projec

<sup>71</sup> Realize. (2016). An environmental scan of publicly-funded rehabilitation services across Canada. Accessed from <http://www.realizecanada.org/wp-content/uploads/Environmental-Scan-of-Rehabilitation-Services.pdf>

When referring a PLWHIV to rehabilitation, one must be cognizant of the services available in the community. There are only a handful of HIV organizations across Canada that currently provide professional rehabilitation. Where formal rehabilitation services are unavailable, referrals to alternative services which support PLWHIV in meeting some of their goals may be appropriate. Local CBHOs may offer wellness programs such as yoga or meditation, massage, access to a social worker or cooking classes. Gyms such as the YMCA often offer exercise programs for people living with chronic illness and may determine fees for service based on a sliding scale which increases access for people with low incomes. It is important to note that referrals to these more informal services should not be considered a reasonable substitute for comprehensive assessment and treatment administered by a skilled rehabilitation professional. Additionally, some multi-disciplinary primary care settings such as family health teams and community health centres may have rehabilitation professionals as members of the team.

With regard to access to rehabilitation, family physicians treating PLWHIV should:

- Be aware of the services available in their community
  - Community health centres
  - Private clinics
  - CBHOs
  - Falls prevention programs
- If there are no services available close by consider a local community centre or YMCA for alternate activities that may serve as a reasonable substitute for professional rehabilitation services
- As the primary care provider, you may need to advocate for creative solutions for your patient to access rehabilitation
  - For example, advocating for your patient to access chronic health condition programs

#### **d. Cost**

Some rehabilitation services, such as those provided to hospital inpatients, are covered by provincial health insurance plans. People may be able to access publicly-funded outpatient rehabilitation services in hospital clinics after discharge from an inpatient unit, but many of these services have been eliminated in the past decade<sup>72</sup>. In certain provinces, PLWHIV may be able to access publicly insured services if they are clients of a home care organization or if they are collecting social assistance as a person living with a disability.

Otherwise, community-based rehabilitation services are not covered under provincial health insurance plans. Sometimes community-based organizations, community health centres and family health teams are able to offer these services free-of-charge to their clients by securing funding to hire a rehabilitation service provider or by working in partnership with another organization. If this is not available, community-based rehabilitation services must be paid for by the patient, either through private health insurance or out-of-pocket. In many cases, these services may be prohibitively expensive for PLWHIV and/or HCV.

With regard to cost, family physicians treating PLWHIV should:

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<sup>72</sup> Auditor General of Ontario. (2013). Ministry of Health and Long-Term Care: 3.08 Rehabilitation Services at Hospitals. Accessed from <http://www.auditor.on.ca/en/content/annualreports/arreports/en13/308en13.pdf>

- Ask about a patient's insurance, whether they receive social benefits, or the ability for them to pay for private services
- In the case that a patient is not able to afford services try referring to:
  - A multi-disciplinary centre, such as a family health team or community health centre, that provides publicly-funded rehabilitation services
- A local community centre or YMCA for alternate activities that may serve as a cost-effective replacement for professional rehabilitation services.
- As the primary care provider, you may need to advocate for creative solutions for your patient to access rehabilitation

#### e. Integrative Medicine

*'Integrative medicine and health reaffirms the importance of the relationship between practitioner and patient, focuses on the whole person, is informed by evidence, and makes use of all appropriate therapeutic and lifestyle approaches, healthcare professionals and disciplines to achieve optimal health and healing'* <sup>73</sup>

In addition to Western medicine, integrative medicine approaches may include acupuncture, aromatherapy, chiropractic care, the use of herbs and/or supplements, homeopathy, massage therapy, meditation, naturopathy, reflexology, Reiki, traditional medicine, and yoga.

Although there are anecdotal reports that certain complementary and alternative therapies (CAMTs) can mitigate the symptoms associated with HIV and the respective pharmacological treatments, the evidence surrounding the effectiveness of these therapies in the context of HIV care remains unclear. <sup>74,75</sup> Since physicians in Canada are trained to engage in evidence-based clinical practices, some are reluctant to refer their patients to complementary health services. In other cases, clinicians are willing to recommend certain therapies, recognizing that they may have some benefit for the patient, are affordable for the patient, and are not likely to result in harm.

For example, in a recent study, 80% of infectious disease specialists cited the lack of clinical evidence of effectiveness as a barrier to referring patients for complementary therapies. <sup>76</sup> Even so, more than half of all physician respondents who were familiar with complementary approaches said they recommend vitamin and mineral supplementation, massage therapy or yoga, and just less than half said they recommend meditation or acupuncture.

Many PLWHIV - approximately 60% according to one literature review - report using these modalities, particularly women. <sup>77,78</sup> Certain kinds of CAMTs, especially herbal remedies, may interact with

<sup>73</sup> Consortium of Academic Health Centers for Integrative Medicine. (2009). Accessed from <https://www.imconsortium.org/about/about-us.cfm>

<sup>74</sup> Rapid Response Service. Rapid Response: Complementary, Alternative and Traditional Medicine in HIV Care. Toronto, ON: Ontario HIV Treatment Network, February 2013.

<sup>75</sup> Verma, S., Thuluvath, P.J. (2007). Complementary and alternative medicine in hepatology: Review of the evidence of efficacy. *Clinical Gastroenterology and Hepatology*, 5(4), 408-416.

<sup>76</sup> Shere-Wolfe, K.D., Tilburt, J.C., D'Adamo, C., Berman, B. & Chesney, M.A. (2013) Infectious diseases physicians' attitudes and practices related to complementary and integrative medicine: results of a national survey. *Evidence-Based Complementary and Alternative Medicine*. Accessed from <http://dx.doi.org/10.1155/2013/294381>

<sup>77</sup> Furler, M.D., Einarson, T.R., Walmsley, S., Millson, M., Bendayan, R. (2003). Use of complementary and alternative medicine by HIV-infected outpatients in Ontario, Canada. *AIDS Patient Care and STDs*, 17(4), 155-168.

<sup>78</sup> Littlewood, R.A., Vanable, P.A. (2008). Complementary and alternative medicine use among HIV-positive people: research synthesis and implications for HIV care. *AIDS Care*, 20(8), 1002-1018.



medications that a PLWHIV may be taking.<sup>79</sup> Furthermore, studies have shown that only about 35% of complementary therapies used by patients are being recorded in their medical records.<sup>80,81</sup> This could indicate missed opportunities for discussion/documentation of symptomatology, effective coping strategies or potentially harmful drug interactions.<sup>82</sup>

With regard to integrative medicine, family physicians treating PLWHIV should:

- Be prepared to discuss the topic of complementary therapies, regardless of whether they are comfortable coordinating an integrative approach to care
- Inquire about patients' cultural, spiritual and linguistic needs and explore how these might impact their access to ongoing care and support; and make appropriate referrals based on their responses and the services available such as to the Canadian AIDS Society or to the organizations listed on CATIE's [Specific Populations](#) page<sup>83</sup>
- Share CATIE's [Practical Guide to Complementary Therapies](#) with the patient<sup>84</sup>

There is currently no evidence to suggest that PLWHIV who engage in complementary or alternative therapies are less adherent to their HIV medications. In fact, engaging in integrative care is likely an indication that a patient is committed to maintaining their overall health and well-being.<sup>85,86</sup>

#### f. Cognitive Impairment

HIV-associated neurocognitive disorder (HAND) is one of the most feared complications of HIV infection, though most people with HIV in the cART era do not experience the most severe form of impairment.<sup>87</sup>

The most recent research classification for HAND was determined by an NIH working group in 2007 which was convened in Frascati, Italy, and is therefore commonly referred to as the Frascati Criteria.<sup>88</sup> The Frascati Criteria allows for three diagnostic categories: asymptomatic neuropsychological impairment (ANI), mild neurocognitive disorder (MND) and HIV-associated dementia (HAD). For each of these HAND diagnoses, an individual must demonstrate at least mild neuropsychological impairment in at least two cognitive domains that is attributable, at least in part, to HIV infection.

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<sup>79</sup> Littlewood RA, Venable PA. A global perspective on complementary and alternative medicine use among people living with HIV/AIDS in the era of antiretroviral treatment. *Current HIV/AIDS Reports* 2011;8 (4):257-68

<sup>80</sup> Cohen, R.J., Ek, K. & Pan, C.X. (2002). Complementary and alternative medicine (CAM) use by older adults: A comparison of self-report and physician chart documentation. *Journal of Gerontology*, 57A(4), M223-M227.

<sup>81</sup> Liu, C., Yang, Y., Gange, S.J., Weber, K., Sharp, G.B., Wilson, T.E. et al. (2009). Disclosure of complementary and alternative medicine use to health care providers among HIV-infected women. *AIDS Patient Care and STDs*, 23(11), 965-971.

<sup>82</sup> Littlewood, R., & Venable, P. (2008). Complementary and alternative medicine use among HIV-positive people: research synthesis and implications for HIV care. *AIDS Care*, 20(8), 1002-1018. <http://dx.doi.org/10.1080/09540120701767216>

<sup>83</sup> CATIE. (n.d.). Special Populations. Accessed from: <http://www.catie.ca/en/prevention/populations>

<sup>84</sup> CATIE. (n.d.) A Practical Guide to Complementary Therapies. Accessed from: <http://www.catie.ca/en/practical-guides/complementary-therapies>

<sup>85</sup> Rapid Response Service. Rapid Response: Complementary, Alternative and Traditional Medicine in HIV Care. Toronto, ON: Ontario HIV Treatment Network, February 2013.

<sup>86</sup> Littlewood, R.A. & Venable, P.A. (2014). The relationship between CAM use and adherence to antiretroviral therapies among persons living with HIV. *Health Psychology*, 33(7), 660-667.

<sup>87</sup> Heaton, R.K., Clifford, D.B., Franklin, D.R., Woods, S.P., Ake, C., Vaida, F. et al. (2010). HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy: CHARTER Study. *Neurology*, 75(23), 2087-96.

<sup>88</sup> Antinori A, Arendt G, Becker JT, Brew BJ, Byrd DA, Cherner M, Clifford DB, Cinque P, Epstein LG, Goodkin K, Gisslen M, Grant I, Heaton RK, Joseph J, Marder K, Marra CM, McArthur JC, Nunn M, Price RW, Pulliam L, Robertson KR, Sacktor N, Valcour V, Wojna VE. Updated research nosology for HIV-associated neurocognitive disorders. *Neurology*. 2007 Oct 30;69(18):1789-99. Epub 2007 Oct 3. PubMed PMID:17914061.

About one third of PLWHIV are affected by ANI which may cause minor functional deficits, though these are not usually perceptible to the individual.<sup>89</sup> The clinical relevance of ANI is currently being debated as at least one study has suggested that the cognitive health of PLWHIV who have ANI may decline earlier, causing symptomatic impairment.<sup>90</sup>

About 12% of PLWHIV have MND which, by definition, interferes with daily function.<sup>91</sup> Specifically, HIV can affect concentration, information processing speed, motor functioning, episodic and prospective memory (ability to plan something and follow through) and executive functioning.<sup>92</sup> Behavioural manifestations may include apathy, social withdrawal, and impaired judgment.

HAND is often under-recognized and under treated, especially since current screening tools are inadequate for identifying milder forms of HAND.<sup>93</sup> The Mind Exchange Working Group recently developed evidence and consensus-based answers to key clinical questions for the management of HAND.<sup>94</sup> Current consensus recommends that "what is good for the heart is good for the brain".<sup>95</sup> It is important to note that according to the Frascati Criteria, the essential feature of HAND is cognitive disturbance; this revision eliminated the possibility of HIV neurocognitive disorders being diagnosed on the basis of neuromotor and noncognitive psychiatric changes such as changes in personality or mood.<sup>96</sup>

EPLWHIV-HCV co-infection experience more substantial neurocognitive deficits than their mono-infected peers. A recent study showed a higher prevalence of multiple neurologic disorders, and more severe HIV-associated cognitive impairment among this population.<sup>97</sup>

As people get older, age-related cognitive issues may also emerge.

With regard to cognitive impairment, family physicians treating PLWHIV should:

- Encourage all patients with HIV or HIV/HCV co-infection to engage in activities that build cognitive reserve
- If cognitive impairment is suspected
  - Refer patients for neuropsychological testing (where available)
  - Refer patients to an occupational therapist who can conduct a home safety assessment and coach an individual on compensatory memory strategies and maintaining social engagement.

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<sup>89</sup> Chiao, S., Rosen, H.J., Nicolas, K., Wendelken, L.A., Alcantar, O., Ranking, K.P. et al. (2013). Deficits in self-awareness impact the diagnosis of asymptomatic neurocognitive impairment in HIV. *AIDS Res Hum Retroviruses*, 29(6), 949-956.

<sup>90</sup> Grant, I., Franklin, D.R., Deutsch, R., Woods, S.P., Vaida, F., Ellis, R.J et al. (2014). Asymptomatic HIV-associated neurocognitive impairment increases risk for symptomatic decline. *Neurology*, 82(23), 2055-62.

<sup>91</sup> Antinori, A., Arendt, G., Becker, J.T., Brew, B.J., Byrd, D.A., Cherner, D.B. et al. (2007). Updated research nosology for HIV-associated neurocognitive disorders. *Neurology*, 69, 1789-1799.

<sup>92</sup> Woods, S.P., Moore, D.J., Weber, E., Grant, I. (2009). Cognitive neuropsychology of HIV-associated neurocognitive disorders. *Neuropsychol Rev*, 19, 152-168.

<sup>93</sup> Zipursky, A.R., Gogolishvili, D., Rueda, S., Brunette, J., Carvalho, A., McCombe, J.A. et al. (2013). Evaluation of brief screening tools for neurocognitive impairment in HIV/AIDS: a systematic review of the literature. *AIDS*, 27 (15), 2385-2401.

<sup>94</sup> Mind Exchange Working Group. Assessment, diagnosis, and treatment of HIV-associated neurocognitive disorder: a consensus report of the mind exchange program. *Clin Infect Dis*. 2013 Apr;56(7):1004-17. doi: 10.1093/cid/cis975

<sup>95</sup> Rourke S. State of the art and emerging measures of neurocognitive health among people living with HIV. Presented at the 2nd International Forum on HIV and Rehabilitation Research. London England. 2014

<sup>96</sup> Gandhi NS, Moxley RT, Creighton J, Roosa HV, Skolasky RL, Selnes OA, McArthur J, Sacktor N. Comparison of scales to evaluate the progression of HIV-associated neurocognitive disorder. *HIV Ther*. 2010 May;4(3):371-379.

<sup>97</sup> Vivithanaporn, P., Nelles, K., DeBlock, L., Newman, S.C., Gill, M.J., Power, C. (2012). Hepatitis C virus co-infection increases neurocognitive impairment severity and risk of death in treated HIV/AIDS. *Journal of the Neurological Sciences*, 312(1-2), 45-51.

Research is underway to see if computer-based ‘brain fitness’ programs are effective for PLWHIV who have neurocognitive impairment.<sup>98</sup>

### **g. Engagement in the Labour Force**

Because of vast improvements in HIV treatment, many PLWHIV today are returning to and/or remaining in the work force, despite HIV-related challenges. While it is unknown how many Canadians living with HIV are employed versus unemployed, a substantial number of Canadians with complex chronic illnesses, including HIV, are willing and able to work.<sup>99</sup>

Stable access to extended drug and health benefits is critical to maintaining good health for someone living with HIV. Individuals who have previously left the workforce and who are receiving social assistance, including health benefits, may be justifiably concerned about the risk of losing these benefits if they return to work. Not only do current income support programs in both the public and private sector present many barriers to flexible work force participation, particularly for people with episodic illnesses such as HIV, but many employers do not provide employee health benefits or limit access by opting for policies with ‘pre-existing condition’ clauses.

Early intervention strategies by family physicians to connect PLWHIV with information and resources related to health and wellness may build confidence that employment can be maintained. At the time of diagnosis, supportive emotion-focused counseling and referrals to rehabilitation providers such as occupational therapists, dietitians and community-based HIV organizations can help patients better understand their illness and strategies to maintain good health. Vocational rehabilitation specialists are able to help newly diagnosed PLWHIV strategize around how to balance their health needs and their work lives. For example, they can provide coaching on how to ask for accommodations in the workplace, and explore the issue of workplace disclosure.

Many individuals living with HIV who have been out of the workforce for many years contemplate returning to work, but find the prospect daunting. They may be concerned that their skills have declined or that they are not up-to-date, that they will face discrimination in the workplace, or that they are not fit enough physically and/or mentally to hold a job. A vocational rehabilitation professional, especially one who is knowledgeable about HIV, can help an individual structure their resume to minimize gaps in employment history, find work that fits their interests and/or capacity (work hours, physical demands, etc.), and provide skills training. Some vocational rehabilitation providers do not have experience working with clients with HIV, but have worked with clients with other disabilities who experience similar concerns.

Volunteering in a field of interest can be a helpful part of a graduated return to work process.

If an individual with HIV is unable to work for a time, they may need assistance applying for income support. Family physicians play an important role in this process if an individual is applying for a disability-related support program since they will need a professional to document their health status on their application.

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<sup>98</sup> Rourke, S.B. (2013). Neurocognitive screening and behavioural interventions for HIV-associated neurocognitive disorders (HAND). Accessed from [http://www.realizecanada.org/wp-content/uploads/S\\_Rourke-CUHRRCPresentationJune132013.pdf](http://www.realizecanada.org/wp-content/uploads/S_Rourke-CUHRRCPresentationJune132013.pdf)

<sup>99</sup> Smith Fowler, H. (2011). Employees’ perspectives on intermittent work capacity: What can qualitative research tell us in Ontario. Accessed from [http://www.srdc.org/uploads/IntermittentWork\\_report\\_EN.pdf](http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf)

Further help completing applications - which are often complex and overwhelming, especially for someone newly diagnosed with a chronic illness - can be provided by local community-based HIV organizations (CBHOs). Family physicians should be prepared to make timely referrals to these services. Many community-based HIV organizations advocate on behalf of individuals accessing income support programs, and some also provide benefits information and/or financial planning services.

With regard to engagement in the labour force, family physicians treating PLWHIV should:

- Provide assistance and documentation as necessary and appropriate in filling out forms for income support
  - Make referrals to CBHOs or other organizations that can provide assistance in completing these forms
- Connect PLWHIV with information and resources related to health and wellness may build confidence that employment can be maintained through referrals to CBHOs, community health centres, local YMCAs or other organizations that provide employment, health, and/or wellness services

#### **h. Mental Health Issues**

PLWHIV experience high rates of depression<sup>100,101</sup> so access to psychological support is of critical importance. Depending on the severity of the mental health issue, and the preferences of the individual, interventions may include: cognitive behavioral therapy, interpersonal psychotherapy, mindfulness-based cognitive therapy, self-help, psychoeducation, medication, a peer support group, or self-care activities.<sup>102</sup> Mental health services offered in the community are preferable to those provided in medical facilities.<sup>103</sup>

For more information about mental health and the role of primary care physicians, please refer to

- The [Mental Health resources](#) on the College of Family Physicians of Canada website<sup>104</sup>

#### **i. Self-Care**

The various comorbidities that may be present in a PLWHIV can lead to self-care impairments.<sup>105</sup> Self-care, including eating well, exercising and accessing social support through a community-based organization may play an important role in the rehabilitation process for a person living with HIV.

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<sup>100</sup> Rusch M, Nixon S, Schilder A, Braitstein, P, Chan K, Hogg RS. Impairments, activity limitations and participation restrictions: Prevalence and associations among persons living with HIV/AIDS in British Columbia. *Health and Quality of Life Outcomes*. 2004 46(2)

<sup>101</sup> Schaefer, M., Capuron, L., Friebe, A., Diez-Quevedo, C., Robaey, G., Neri, S. et al. (2012). Hepatitis C infection, antiviral treatment and mental health: A European expert consensus statement. *Journal of Hepatology*, 57(6), 1379-1390.

<sup>102</sup> The Australian Psychological Society Ltd. (2010). Evidence-based psychological interventions in the treatment of mental disorders: A literature review. Third Edition. Accessed from <http://www.psychology.org.au/assets/files/evidence-based-psychological-interventions.pdf>

<sup>103</sup> Mental Health Commission of Canada. (2012). Changing Directions, Changing Lives: The Mental Health Strategy for Canada. Accessed from <http://strategy.mentalhealthcommission.ca/pdf/strategy-text-en.pdf>

<sup>104</sup> College of Family Physicians of Canada. (2012). *Mental Health*. Accessed from <http://www.cfpc.ca/ProjectAssets/Templates/Resource.aspx?id=1596&langType=4105>

<sup>105</sup> Misko, A., Nelson, D., & Duggan, J. (2014). Three Case Studies of Community Occupational Therapy for Individuals with Human Immunodeficiency Virus. *Occupational Therapy In Health Care*, 29(1), 11-26. <http://dx.doi.org/10.3109/07380577.2014.941452>

Physicians can refer patients to a physiotherapist or occupational therapist for assessment and treatment. Treatment for self-care impairments can include exercise, energy conservation, or a focus on improving participation in social activities or activities of daily living<sup>106,107,108</sup>

Community-based HIV organizations offer a range of programs including services such as food banks or community kitchens, individual or group counselling, drop-in programs, and case management. They are safe spaces where PLWHIV can talk openly about their HIV status and learn from others' experiences.

With regard to self-care, family physicians treating PLWHIV should:

- Refer patients to local CBHOs, community health centres, occupational therapy or physiotherapy as appropriate

## 8. Conclusion

Rehabilitation is a critical but often overlooked, under-valued, and under-utilized component of the continuum of optimal care for PLWHIV. Rehabilitation can provide critical supports to people who are experiencing pain, mobility problems, and/or other mental or physical challenges that may prevent them from participating fully in society.

Incorporating rehabilitation into the care, treatment and support of PLWHIV is critical to helping them achieve optimal health. Further, rehabilitation professionals (physiotherapists, occupational therapists, speech-language pathologists, and physiatrists) are valued members of the interdisciplinary health team. Collaborative care is a model well-suited to provide the best possible primary care to people with complex chronic diseases, including HIV.

For additional resources, information and links, visit the *Realize* website at [www.realizecanada.org](http://www.realizecanada.org). Specifically, there are two decision tools available that can help you and your patients determine if rehabilitation supports are right for them:

- [Information for Service Providers on Rehabilitation Supports for People Living with HIV & Hepatitis C](#)
- [Rehabilitation Supports for People Living with HIV & Hepatitis C](#)

## 7. POTENTIAL REFERRALS - REHABILITATION PROVIDERS

### Why refer to a Physiotherapist?

Physiotherapists (Physical Therapists) are regulated health professionals that help restore movement and function to full potential when somebody is affected by injury, illness or disability. Physiotherapists develop, maintain and restore health for people of all ages, helping people to manage their conditions

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<sup>106</sup> O'Brien K, Nixon S, Tynan AM, Glazier R. Aerobic exercise interventions for adults living with HIV/AIDS. Cochrane Database Syst Rev. 2010a/b Aug4;8:CD001796. Review. PubMed PMID: 20687068. <http://www.ncbi.nlm.nih.gov/pubmed/20687068>

<sup>10</sup> O'Brien K, Tynan MA, Nixon S, Glazier RH. Effects of Progressive Resistive Exercise in Adults Living with HIV/AIDS: Systematic Review and Meta-Analysis of Randomized Trials. AIDS Care. July 2008; 20(6): 631-653.

<sup>108</sup> Misko, A., Nelson, D., & Duggan, J. (2014). Three Case Studies of Community Occupational Therapy for Individuals with Human Immunodeficiency Virus. Occupational Therapy In Health Care, 29(1), 11-26. <http://dx.doi.org/10.3109/07380577.2014.941452>

and prevent disease. Physiotherapy takes a holistic approach that involves the patient directly in their own care, encompassing physical, psychological, emotional and social well-being.

In the context of HIV, there are multiple opportunities for disease prevention and rehabilitation interventions by physiotherapists, whether in hospital settings, outpatient services or in the community. As experts in movement and function with a thorough knowledge of pathology and its effects on body systems, physiotherapists will provide interventions, including exercise, to enable PLWHIV to self-manage and achieve a better quality of life.

Physiotherapists can assist with a range of health challenges including pain, fatigue, breathlessness, mobility issues, reduced balance or coordination, muscle weakness, reduced flexibility, reduced exercise tolerance, deconditioning, low mood and impacts on quality of life. Physiotherapists can also assist in supporting patients to overcome barriers to participating in a more active lifestyle which will assist in managing common chronic illnesses such as diabetes, obesity and cardiovascular disease.

### **Why refer to an Occupational Therapist?**

An occupational therapist is a regulated health professional who has specific expertise in helping people retain their independence and engage in activities that they need to or want to do, including self-care, work or leisure pursuits. Occupational therapists work with clients, either individually or in groups, in a variety of settings including hospitals, outpatient clinics, schools and people's homes or workplaces. They help people identify personal goals and strategize about how to achieve these goals.

Examples of occupational therapy interventions that may prove helpful for PLWHIV or related illnesses include: energy conservation strategies, seating/mobility needs, home/office/environmental modifications, adaptive devices and resources that address activities of daily living (ADL) and instrumental activities of daily living (IADL). Occupational therapists also conduct assessments of physical spaces (offices, homes) and make recommendations about how to ensure they are safe and accessible for the people who use them.

### **Why refer to a Psychiatrist?**

A Psychiatrist, or Specialist in Physical Medicine and Rehabilitation, is a specialist physician. Psychiatry is a broad discipline with many sub-specialties that were initially developed to address the needs of injured veterans returning from the World Wars. Residency training includes knowledge and skills-building from the disciplines of internal medicine, orthopaedics and neurosurgery, rheumatology and neurology. Core competencies are gained in the domains of stroke, spinal cord injury, traumatic/acquired brain injury (including MS), neuromuscular degenerative disorders and electrodiagnosis, musculoskeletal/sports medicine, chronic pain and amputations and pediatric rehabilitation.

HIV can affect the central nervous system, peripheral nervous system and the muscles. The peripheral nervous system may also be affected by HIV treatment. PLWHIV can therefore experience problems with mobility, hand function, bowel and bladder function and pain. In addition, generalized deconditioning and fatigue and secondary complications of immobility may be relevant among those with more advanced HIV disease.

In response to these issues, a physiatrist will take a holistic approach, providing symptom management, treating complications of immobility, and providing guidance on maximizing function through the use of appropriate pharmacotherapy, orthotic/prosthetic and mobility devices and aids, exercise prescriptions, and recommended modalities and/or environmental modifications.

In some cases, the Physiatrist may act as a primary care physician to a person with disabilities and follow them longitudinally for a protracted or indefinite period.

### **Why refer to a Dietitian?**

Registered Dietitians are regulated healthcare professionals. Dietitians may work with clients within the hospital setting, primary care clinics and the community. Dietitians use knowledge and skills in food and nutrition to contribute to well-being and longevity by optimizing nutritional intake and promoting healthy lifestyles.

Goals of nutrition intervention for individuals living with HIV include:

- identification of malnutrition risk and prevention of nutrient deficiencies
- maintenance of nutritional status including lean body mass
- management of nutrition related symptoms of HIV
- management of treatment side effects
- prevention of food borne illness
- management of co-morbid conditions such as; diabetes, hyperlipidemia, decreased bone mineral density
- improvement of food security via community food programs

### **Why refer to a Speech-Language Pathologist?**

Speech-Language Pathologists (SLP) are regulated health professionals who deal with disorders of communication and swallowing. SLPs work with people of all ages who have communication disorders resulting from a variety of impairments, both congenital and acquired. Depending on the impairment, SLPs may work independently or as part of a health care team.

In the context of HIV, there are many potential situations where the services of an SLP may be helpful, especially as the impairments become more severe and communication of a person's wants and needs are crucial to their care, wellbeing and control.

Specific conditions which may impact PLWHIV include feeding and swallowing problems. In addition, PLWHIV may experience the same conditions that create communication impairments for anyone as they age, for instance strokes and neurodegenerative diseases such as Parkinson's disease. SLPs are trained to provide diagnostic information and interventions in response to these impairments. They can also play a critical role at the end of life if speech is compromised, helping people make use of an augmentative or alternative communication system.

### **Why refer to a Vocational/Employment/Career Counsellor?**

Employment and/or Career Counsellors are not regulated in Canada although a group of industry professionals are currently proposing national guidelines for self-regulation. At a minimum, counsellors will have attained specialized post-secondary education and training specific to career and vocational services. Individuals may also have a Master of Arts in (Vocational Rehabilitation) Counselling, a Rehabilitation Services Certificate, or another vocational rehabilitation certification.

Practitioners may be employed in social services environments, government-funded employment programs or private firms or they may work independently. Practitioners may work with the general population, or possess expertise in the needs of specific populations (e.g. people living with disabilities, newcomers, youth) or industries. Work is often done in a combination of one-on-one and group settings.

The employment needs of PLWHIV have changed as the epidemic has shifted. While the immediate goal in the early years was to register PLWHIV for disability supports, today Vocational Counsellors help individuals manage the complexities of employment and an episodic illness over the course of their working life. Career Counsellors can help PLWHIV make informed decisions when seeking work, whether for the first time or after a period of unemployment or underemployment. They can also inform PLWHIV about their rights in the workplace and explain the complexities of working with a disability.

Employment Counsellors work with their client to develop and implement a realistic vocational plan. They review work history and help identify any barriers or challenges to employment, including gaps, training needs, and other health concerns. They can provide a suite of tools to assist jobseekers including:

- Career planning and assessments
- Résumés and cover letters
- Interview coaching
- Benefits counselling
- Job search resources and placement supports
- Training opportunities and skills upgrading
- Support assessing the pros/cons of disclosure
- Tips for requesting accommodations
- Job maintenance support

## **Why refer to a Recreation Therapist?**

“The purpose of Therapeutic Recreation (TR) is to enable individuals to achieve quality of life and optimal health through meaningful participation in recreation and leisure. The profession recognizes the importance of the recreation experience and supports all individuals in having full access to and the freedom to choose recreation and leisure opportunities.”<sup>109</sup>

Recreation Therapists can help PLWHIV identify and develop healthy interests, minimize the impact of social isolation, build and practice life skills, engage in physical rehabilitation through activity, improve quality of life through leisure activity, and connect to community resources. Outcomes of recreation therapy interventions may include improved physical and cognitive abilities, increased confidence and

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<sup>109</sup> Therapeutic Recreation Ontario. (n.d.) Definition of Therapeutic Recreation. Accessed from <https://www.trontario.org/about/about-therapeutic-recreation.html>



self-esteem, greater involvement in the community, strengthened interpersonal skills and relationships, improved coping and adaptation skills, and realization of the benefits of a healthy leisure lifestyle.

Recreation Therapists work in a variety of settings with a variety of populations, including hospitals, rehabilitation programs, long-term care facilities, day programs, mental health centres, and children’s treatment centres.

### Are your patients using complementary therapies?

Complementary and alternative medicines and therapies (CAMT) fall outside of conventional Western medicine and are widely used by PLWHIV. Since the use of CAMTs may have an impact on the overall treatment plan, care providers need to educate themselves on the wide range of complementary therapies available, ask patients whether they are accessing these services and remain up to date on the evidence surrounding their effectiveness in the context of HIV. Some PLWHIV find that CAMTs are helpful in addressing some of the physical, mental or emotional challenges they face.<sup>110</sup> Some of these CAMTs include:

Acupuncture	Massage Therapy	Homeopathy
Naturopathy	Aromatherapy	Chiropractic Treatments
Yoga, Meditation, Tai Chi	Reiki	Traditional Medicine

Traditional medicine, the “*sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness.*”<sup>111</sup> Engagement with traditional medicine is a particularly relevant consideration in the Canadian context given the importance of Traditional Healing within Indigenous culture, and among members of the many other cultural communities that make up our diverse population.

CAMTs, including traditional medicine, are an essential part of bridging the gap between primary medical providers and achieving/maintaining higher standards of quality of life. They provide a necessary view of individuals in a holistic manner incorporating not only therapy for symptomatic relief, but also considering impacting lifestyle factors (structural alignment, dietary, psycho-emotional, spiritual, etc.) which fall outside of the scope of conventional medical services.

CAMTs have been used in the management, and in certain situations resolution, of a wide variety of chronic conditions including:

- Acute/chronic musculoskeletal pain
- PTSD/trauma
- Hormonal imbalance
- Body chemistry (i.e. thrush, yeast infections, skin conditions)

<sup>110</sup> Pawluch, D, Cain, R, Gillett, J. Lay constructions of HIV and complementary therapy use. *Social Science and Medicine*. 2000 51(2): 251-64.

<sup>111</sup> WHO. (n.d.). *Traditional Medicine: Definitions*. Accessed from <http://who.int/medicines/areas/traditional/definitions/en/>

- Respiratory conditions
- Digestive disorders
- Stress management
- Addictions, long-term substance use
- Minimizing/managing side effects of medications
- Post-surgical recovery

They are an attractive alternative for pharmaceutical therapies and/or surgical interventions, especially in situations where such therapies are unsuccessful, too high risk or not viable due to toxic effects on the kidney and/or liver for individuals with pre-existing organ damage. Additionally, while certain advanced stage health conditions have progressed to a point of irreversible damage and degeneration, CAMTs can still be safely implemented simply to assist with day-to-day function and quality of life.

## 8. Case Studies

### Case # 1: John - Diabetes, Neuropathy, Substance Misuse

John, 46, is a new patient in your clinic referred by a community health nurse. He does not have a family physician and has been using walk-in clinics for his care. He was recently hospitalized for a drug overdose when the nurse found him unconscious in his apartment during a regularly scheduled home visit. He has also been hospitalized for two drug-related admissions in the past 18 months. He has declined follow-up with the addictions team due to his concerns about worsening his pain.

John has a six-year known history of documented HIV and HCV. He does not want to take antiretroviral medication as he is afraid his roommates will learn of his HIV status and ask him to leave. He also has a fifteen year history of diabetes and as a result had a left below knee (transtibial) amputation 4 years ago. He usually wears a prosthesis. Two years ago he was admitted to the ICU for sepsis from a wound infection on his stump. John is currently only being followed by a community health nurse for dressing changes for a second non-healing wound on the stump. As a result, he has not been able to use his prosthesis and lately has been using a wheelchair for outdoor mobility and crutches in his apartment.

He has long-standing peripheral neuropathy, which leaves him with pain and decreased sensation in his lower extremities and hands. Balance is poor. He tells you that he has good days and bad days. His energy levels fluctuate and some days he needs to sleep in the afternoon for 2 to 3 hours and he does not want to exert himself in any way. He has been on long-term disability for 5 years.

Upon entering the exam room, he is alert and oriented but appears emaciated and agitated. John demonstrates he is fully capable of transferring onto the examination table but does so impulsively and recklessly, without regard for use of safety features such as the brakes on his wheelchair or consideration of the positioning of the chair.

#### Medical Assessment and Plan of Care:

- Baseline medical screening, including liver, renal, thyroid and white and red blood cell function, would be helpful to assess possible additional cause of fatigue, e.g. underlying wound infection. As well, reassessing his immunological status could further guide treatment options, if not done at time of recent hospitalization.

- Referral to a prosthetist or physiatrist (i.e. his prior prosthetic rehabilitation team) could be considered for modifications to his prosthesis that might prevent further wound breakdown or even allow limited use of his prosthesis.
- John may require a referral for a HIV-Associated Neurocognitive Disorder (HAND) assessment. If the assessment is positive, you may consider a CT head scan to rule out focal frontotemporal pathology as John is behaving in an erratic and disinhibited fashion. Other work-up may be useful, most prominently formal, in-office depression screening, as this is a fairly easily treated cause of his fatigue.
- However, an in-home based functional assessment may prove the more useful for preventing subsequent falls. Since he has had three admissions for drug overdoses recently, you might discuss the importance of a referral to a detoxification centre, addictions counselling, or twelve-step programs. Significant education and support across all facets of his life may be required before he agrees to this.
- John has identified pain management of his polyneuropathy-related pain as a major problem. Longer-acting narcotics (e.g. methadone) could be considered. Exploring non-narcotic options, both pharmacological and non-pharmacological, would help him in multiple ways.
- Typical medications for diabetic nerve pain, including Gabapentinoids, Tricyclics, Nabilone, Serotonin–norepinephrine reuptake inhibitors (SNRIs), and Anti-epileptics, could be reviewed. Topical creams (Capsicum, Lidocaine) could be considered. Mirror imagery for phantom limb pain, if present, could be done. Other non-pharmacological treatment trials could involve transcutaneous nerve stimulation (TENS) from a physiotherapist, acupuncture, or structured pain management counselling. Best options for success here will require multiple modalities in approach.
- As John is a diabetic, nutrition support is crucial – referral to a dietitian or community food program is likely warranted, as a lack of glycemic control is probably contributing to his poor wound healing and neuropathy.
- John could benefit from the array of programs and social supports provided by Community-based HIV and/or HCV organizations. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology <https://HIV411.ca/>
- Consider and inquire as to the CAMTs that John may be accessing.
- Inquire about John’s cultural, spiritual and linguistic needs and how these might impact his access to ongoing care and support; make appropriate referrals based on his responses and the services available.
- Overall, John will benefit from a plan to increase his social supports and his understanding of his health conditions, with a goal to eventually consider return to some type of employment/ meaningful activity.

## Case # 2 Stella - Managing Episodic Disabilities, Return to work

Stella is a 58 year-old female who was diagnosed with HIV 20 years ago. She is taking combination antiretroviral therapy. Her CD4 count is 520 cells/mm<sup>3</sup> and her viral load is undetectable. Stella is able to negotiate stairs, but gets short of breath climbing one flight of stairs. Stella is a smoker (1 pack per day for the past 30 years) and has longstanding Chronic Obstructive Pulmonary Disease (COPD) with exacerbations every few months. She continues to suffer from bilateral peripheral sensory neuropathy in her feet that began when she started antiretroviral therapy 15 years ago and which never resolved. A

recent bone mineral density scan (BMD) showed accelerated bone mineral loss in several areas, likely related to earlier antiretroviral use.

Stella reports experiencing fluctuating “good days” and “bad days”. On the “bad days”, Stella wakes up feeling unable to get out of bed. She feels too weak and exhausted to move around her house, shop for groceries, or leave her home. On these days she barely manages to make a meal for herself. At times she finds herself feeling down, isolating herself from others, and worrying about the uncertainty of her future. On the “good days”, Stella cleans her house from top to bottom without taking any rests. She reports that cleaning helps her feel “productive” and “alive”. After cleaning, however, Stella is exhausted and requires time to recover in bed.

She helps her 79 year old mother when possible, such as attending medical appointments with her.

Stella is considering returning to work, as she is finding it more and more difficult to provide for herself solely on provincial income support funding. However she is unsure whether she can handle full time work. She is concerned about the gap in her resume, her age, and is hesitant to disclose her HIV status to potential employers for fear that she may be discriminated against.

### **Medical Management:**

Stella is a patient living with HIV but also with a number of other complicating medical comorbidities that are contributing to her difficulty managing. She requires a full assessment of each of these issues in order to truly optimize her function at home and make return to work a possibility.

- You ensure that Stella is on the appropriate puffers, has recent pulmonary function tests, and you discuss with her the possible referral to a COPD outreach program and/or formal pulmonary rehabilitation. Transportation access programs may help her participate more fully.
- Smoking cessation/reduction programs should also be encouraged.
- Given her smoking history and HIV status, she should also be evaluated for cardiac-associated dyspnea with a thorough history, stress test and echocardiogram.
- Given her decreased BMD, you recommend supplementation with vitamin D, calcium and bisphosphonate therapy (if required).
- Because of her longstanding peripheral neuropathy, Stella should do daily foot checks and see a foot care specialist, such as a Chiropodist/Podiatrist to be fitted with appropriate footwear/orthotics, so as to avoid development of neuropathic ulcers.
- If Stella’s condition persists, you may consider depression assessment, or even referral to a community psychologist or psychiatrist. Stella may then benefit from cognitive behavioural therapy or initiation of medication.

### **Plan of Care**

- You review the principals of pacing and discuss the start of an exercise program as there is good evidence to support the role for aerobic and resistive exercise in the management of HIV as well as in COPD. If available, referral to a community Physiotherapist could assist in establishing appropriate self-management strategies.
- Stella would benefit from educational support regarding how to deal with the episodic nature of her disease(s), especially if she is considering a return to work. Referral can also be made to local vocational reintegration services if available. The HIV411 website has links to employment and financial services <https://aso411.ca/>.

- Clarifying policies about loss of supports if she were to return to work would be helpful for her. For example, Canadian Pension Plan Disability program has a window period for return to prior benefits immediately if a return to work fails within the first three months. Other provincial and private disability programs may have similar options.
- Stella may also benefit from educational support for living with HIV and concurrent conditions. There are several on-line, high quality resources available. Stella can access the Managing Your Health resource and other consumer friendly products published by CATIE <http://www.catie.ca/en/practical-guides/managing-your-health>
- To improve her level of social support, Stella may benefit from a referral to a local Community Based HIV Organization. CATIE maintains a web portal listing organizations and services for people living with and at risk of HIV and hepatitis C in Canada, using Google Maps technology <https://hiv411.ca>.
- Consider and inquire as to the CAMTs that Stella may be accessing
- Inquire about Stella's cultural, spiritual and linguistic needs and how these might impact her access to ongoing care and support; make appropriate referrals based on her responses and the services available

### **Case # 3 Louis - Aging, Cognition, Community**

Louis is a 63 year-old male living with HIV. Louis is an unmarried, shy gay man who came out ten years ago. He was diagnosed with HIV infection approximately two years ago. Currently his viral load is slightly above detectable and with a CD4 count of 450 cells/mm<sup>3</sup> Louis is currently considering his HIV specialist's recommendation to start combination antiretroviral treatment. Louis has a history of cardiovascular disease and bipolar affective disorder and to date has been compliant with treatment. Louis lives alone in a one-bedroom apartment downtown. He is a retired musician who stopped giving private lessons four months ago due to deteriorating health. He denies drug or alcohol misuse.

During a regular follow-up visit with you he reports that he has a companion, Paul, who assists him with grocery shopping and errands. He recently had to sell his prized cello to pay for Paul's services. Louis is concerned as Paul uses his credit card to buy his groceries. Louis reports that he has been having difficulty moving about and using the bus, so is now "housebound". Paul reports that he finds himself more forgetful than usual and that his attention span seems like it is "all over the place", which is impacting the few things that give him pleasure, such as reading and watching television. During the visit with you, Louis demonstrates difficulty with ambulation and balance and he uses the furniture and walls to provide support for walking. He demonstrates decreased lower extremity strength and upper extremity strength bilaterally.

#### **Medical Assessment and Plan of Care:**

Based on his presentation, Louis may have some degree of HIV Associated Neurocognitive Disorder, (HAND), particularly the more common and less severe form known as HIV Associated Mild Neurocognitive Disorder (HA-MND). You:

- Refer Louis to a community Occupational Therapist (OT) to undertake functional neurocognitive testing and assessments of Louis' function including assessing his physical, sensory and cognitive impairments and abilities. These assessments include both formal tests using pen and paper tasks, and a functional task of preparing a light snack and a drink. The pen and paper assessment

indicates areas of impairment and provides a repeatable, scored outcome measure, while the functional assessment indicates activity limitations. Together they describe a picture of overall functioning and enable the therapist to extrapolate to how performance may be affected across a variety of everyday activities.

- Initiate a work-up to rule out reversible causes of his cognitive decline. At minimum he should have blood work for electrolytes/extended electrolytes, TSH, B12, folate, syphilis serology and a CT head scan to rule out hydrocephalus, cerebrovascular disease or space occupying lesions.
- You ensure that Louis continues follow-up with his HIV specialist by referring him for assisted transportation services.
- Consider and inquire as to the CAMTs that Louis may be accessing
- Inquire about Louis's cultural, spiritual and linguistic needs and how these might impact his access to ongoing care and support; make appropriate referrals based on his responses and the services available

### **On follow-up:**

- From the assessment, the OT reports that Louis is grossly oriented and his fund of stored knowledge (remote recall) is also grossly unimpaired. His ability to attend to most tasks is also grossly intact although during the kitchen task he had difficulty attending to more than one task at a time (divided attention). Constructional ability on the formal task and fine motor control on the functional task were both impaired, suggesting that there is an impairment of cognitive motor function, while he has generally intact verbal fluency. Some impairment to recent recall was noticed on formal testing but was less apparent in the functional task. The most significant impairments however are to judgment, planning and organization, which are poor on both the functional and formal assessments. Louis' ability to self- evaluate his performance is also impaired which affects the level of insight into the difficulties he is having. The functions of judgment, planning, organization, self-evaluation and insight together are executive functions and the OT reports that individuals with impairments in these areas are at increased risk of financial abuse from other people or may manage their own finances poorly, often have poorer health self-management as they have poor insight into the need for medication or other self-management strategies, and are at risk of self-neglect including not maintaining a hygienic home environment, not monitoring safety and not monitoring sell-by dates of foods.
- The OT also completed an assessment of the home environment and finds many trip hazards from cluttered furniture and recommends that these are moved or removed. His home has not been cleaned in some time.
- You discuss with the local geriatrics unit/memory clinic whether they would consider seeing him for his cognitive dysfunction despite his young age.
- You perform a formal capacity assessment and assist Louis in identifying an appropriate Power of Attorney/Substitute Decision Maker immediately. This may result in referral to the office of the Public Trustee, or local equivalent. A social worker may be helpful if available.
- Your plan is also to submit a referral to a community access program to assess for whether he would qualify for better assistance programs (for example, home care to support hygiene and household cleaning).
- Eventually you will discuss with Louis the possibility of retirement homes and long-term care and provide information about local options.

## Recommended Reading:

1. A thorough overview of rehabilitation services is provided by **Realize's** *E-module for Evidence-Informed HIV Rehabilitation*, available on line at [www.realizecanada.org](http://www.realizecanada.org)
2. *Primary Care Guidelines for the Management of HIV/AIDS in British Columbia* (Primary Care Guidelines Panel, BC Centre for Excellence in HIV/AIDS) – 2015  
[http://www.cfenet.ubc.ca/sites/default/files/uploads/primary-care-guidelines/primary-care-guidelines\\_015-09-15.pdf](http://www.cfenet.ubc.ca/sites/default/files/uploads/primary-care-guidelines/primary-care-guidelines_015-09-15.pdf)
3. The Cleveland Clinic Centre for Continuing Education – [HIV for the Primary Care Physician](#). (2013)  
Written by: Marisa Tungsiripat.

## Reference Materials:

- 1) To find out more about Physiatry, contact Dr. Tania Bruno at [tania.bruno@uhn.ca](mailto:tania.bruno@uhn.ca)
- 2) To find a vocational rehabilitation support counselor in your region with experience working with clients with disabilities, contact the Vocational Rehabilitation Association of Canada at [info@vraCanada.com](mailto:info@vraCanada.com) or visit their website, <https://www.vraCanada.com/>
- 3) [www.HIV411.ca](http://www.HIV411.ca) can help you find HIV and HCV services in your area.
- 4) PLWHIV with questions about work or insurance can be referred to the 'Resources' section of the **Realize** website at <http://www.realizecanada.org/en/resources/>
- 5) CATIE: Canada's Source for HIV and hepatitis C information. [www.catie.ca](http://www.catie.ca)