



# Care of People Aging with HIV: Northeast/Caribbean AETC Toolkit

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This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under cooperative agreement #U1OHA29291, Regional AIDS Education and Training Centers. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

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This toolkit is designed for clinicians and other professionals who care for people aging with HIV. It provides links to screening and assessment instruments, along with programs and papers that offer clinically useful materials. It is not designed for research. References that are specific to HIV-infected populations are denoted with an asterisk.

We will update this list regularly, and we welcome suggestions. Please send suggestions to [necaetcc@columbia.edu](mailto:necaetcc@columbia.edu).

## **I. General Materials for Patients Aging with HIV**

- a.** \*Graying of AIDS:  
<http://agrayingpandemic.org/>
- b.** \*HIV & Aging Resources from the National Resource Center on LGBT Aging:  
<http://www.lgbtagingcenter.org/resources/index.cfm?s=12>
- c.** National Institute on Aging “Health and Aging” website:  
<https://www.nia.nih.gov/health>
- d.** \*Sexuality and Aging:  
<http://ageisnotacondom.org/en/home/>
- e.** \*CDC HIV among people aged 50 and over:  
<https://www.cdc.gov/hiv/group/age/olderamericans/index.html>

## **II. Caregiving**

- a.** Screening tools for caregiver burden
  - i.** Zarit Burden Interview – 12 item (shortened from original 29 item scale - Michel Bédard et al, 2001: <https://doi.org/10.1093/geront/41.5.652>
  - ii.** Caregiver Self-Assessment Questionnaire (AMA, 2009) (not as well studied):  
<http://www.healthinaging.org/resources/resource:caregiver-self-assessment/>
  - iii.** Modified Caregiver Strain Index (Thornton and Travis, 2003):  
<https://consultgeri.org/try-this/general-assessment/issue-14>
- b.** Resources
  - i.** National Institute on Aging Caregiving Resources:  
<https://www.nia.nih.gov/health/featured/caregiving>
  - ii.** Next Step in Care (has guides and checklists in multiple languages):  
<http://www.nextstepincare.org/>

- iii. VA Caregiver Support: <http://www.caregiver.va.gov/>
- iv. Family Caregiver Alliance: <https://www.caregiver.org/>

### III. Bone Health

- a. \*Reviews with useful algorithms for detection and management of low bone density and osteoporosis:
  - i. McGinty T, Mallon P. (2016) Protecting bone in long-term HIV positive patients receiving antiretrovirals, *Exp Rev Anti-infect Ther.* 2017; 14:6,587-599, DOI: 10.1080/14787210.2016.1184570
  - ii. Brown TT, Hoy J, Borderi M, Guaraldi G, Renjifo B, Vescini F, Yin MT, Powderly WG. Recommendations for evaluation and management of bone disease in HIV. *Clin Infect Dis.* 2015 Apr 15;60(8):1242-51. doi: 10.1093/cid/civ010.
- b. FRAX (an on-line calculator for fracture risk): <https://www.shef.ac.uk/FRAX/>  
(nb: even when listing HIV as a secondary cause of osteoporosis, the FRAX lacks sensitivity: \*Yin MT, et al. Fracture Prediction With Modified-FRAX in Older HIV-Infected and Uninfected Men. *J Acquir Immune Defic Syndr.* 2016 Aug 15;72(5):513-20. doi: 10.1097/QAI.0000000000000998).

### IV. Polypharmacy

- a. Stop/Start toolkit to help avoid both inappropriate medications and omission of appropriate ones:  
[https://www.networks.nhs.uk/nhs-networks/nhs-cumbria-ccg/medicines-management/guidelines-and-other-publications/Stop\\_start\\_pdf\\_final\\_Feb\\_2013\\_version.pdf](https://www.networks.nhs.uk/nhs-networks/nhs-cumbria-ccg/medicines-management/guidelines-and-other-publications/Stop_start_pdf_final_Feb_2013_version.pdf)  
  
Background reference for Stopp/Start: <https://doi.org/10.1093/ageing/afu145>
- b. Beers criteria for potentially inappropriate medications:  
<http://bcbpsd.ca/docs/part-1/PrintableBeersPocketCard.pdf>
- c. *Medications and Older Adults* (Health in Aging). This site has educational materials for patients (note that it has not updated the Beers criteria to 2018):  
<http://www.healthinaging.org/medications-older-adults/>

### V. Elderly Mistreatment and Financial Abuse

- a. Identifying and reporting scams and fraud:  
<https://www.usa.gov/stop-scams-frauds>
- b. National Center on Elder Abuse links to state resources (includes Puerto Rico and USVI): <https://ncea.acl.gov/resources/state.html>



## VI. Medicare and Medicaid

- a. Federal Medicare website for the public:  
<https://www.medicare.gov/>
- b. Federal Medicaid website for the public:  
<https://www.medicaid.gov/medicaid/eligibility/medicaid-enrollees/index.html>
- c. Medicare Rights Center (non-profit consumer service organization):  
<https://www.medicarerights.org/>
- d. Center for Medicare Advocacy: <http://www.medicareadvocacy.org>

## VII. Legal Problems

- a. Carrns A. Feb 8, 2017 *New York Times*. *Why you should get around to drawing up a will*:  
[https://www.nytimes.com/2017/02/08/business/how-to-make-a-will.html?\\_r=0](https://www.nytimes.com/2017/02/08/business/how-to-make-a-will.html?_r=0)
- b. Tools from Lambda Legal (includes wills, trusts, health care wishes and other areas): <http://www.lambdalegal.org/publications/take-the-power>
- c. Advance Directives: General
  - i. Elder Locator Advance Care Planning Fact Sheets:  
[http://www.eldercare.gov/eldercare.NET/Public/Resources/Advanced\\_Care/Index.aspx](http://www.eldercare.gov/eldercare.NET/Public/Resources/Advanced_Care/Index.aspx)
  - ii. National Healthcare Decisions Day Conversation Project (includes links to other resources):  
<http://www.nhdd.org/public-resources/-where-can-i-get-an-advance-directive>
  - iii. American Bar Association Resources:  
[http://www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/consumers\\_toolkit\\_for\\_health\\_care\\_advance\\_planning.html](http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumers_toolkit_for_health_care_advance_planning.html)
  - iv. American Bar Association links to state forms (does not include PR or USVI):  
[http://www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/Stateforms.html](http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/Stateforms.html)
  - v. National Hospice and Palliative Care Organization State Specific Advance Directives (includes PR – in English), but not VI):  
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289>
  - vi. VA Resources:

[https://www.va.gov/GERIATRICS/Guide/LongTermCare/Advance\\_Care\\_Planning.asp](https://www.va.gov/GERIATRICS/Guide/LongTermCare/Advance_Care_Planning.asp)

- vii. POLST (Physician Orders for Life-sustaining Treatment):  
<http://polst.org/programs-in-your-state/>
- d. Advance Directives by State and Territory
  - i. Health care proxy – New York State (multiple languages):  
[https://www.health.ny.gov/professionals/patients/health\\_care\\_proxy/](https://www.health.ny.gov/professionals/patients/health_care_proxy/)
  - ii. Durable power of attorney for health care – New Jersey:  
<http://www.nj.gov/health/advancedirective/ad/forums-faqs/>
  - iii. Generic Advance Directives for Puerto Rico and U.S Virgin Islands:  
<http://www.lifecaredirectives.com/statutory.html>

### **VIII. Assessment Tools**

#### **a. Comprehensive Geriatric Assessment**

- i. Tinetti et al. The Geriatrics 5M's: A new way of communicating what we do. J Am Geriatr Soc. 2017; 65:2115. Doi: 10.1111/jgs.14979
- ii. Tatum et al. Geriatric Assessment: An Office-Based Approach. Am Fam Physician. 2018;97(12):776–784.  
<https://www.aafp.org/afp/2018/0615/p776.html>

#### **b. Basic Activities of Daily Living and Instrumental Activities of Daily Living:**

There are many tools to document basic function. Among the most widely used in primary care are the Katz and Lawton scales – here described in the “Try This” Series of the Hartford Institute of Geriatric Nursing.

- i. <https://consultgeri.org/try-this/general-assessment/issue-2>
- ii. <https://consultgeri.org/try-this/general-assessment/issue-23>

#### **c. Disability/Quality of Life:** Most of these tools have been designed for research and are not feasible in a routine office visit. Consider using a few select questions to document the patient’s overall sense of well-being.

- i. The CDC offers health related quality of life measures in English and Spanish
  - a. <https://www.cdc.gov/hrqol/methods.htm#2>
- ii. The FACIT measures have been designed for research in many diseases and conditions but may help. One can use a tool specific to comorbidity, symptom, treatment or to HIV: \*FAHI (Functional assessment of HIV infection)  
<http://www.facit.org/FACITOrg/Questionnaires>
- iii. WHOQOL-BREF



[http://www.who.int/mental\\_health/publications/whoqol\\_hiv\\_bref.pdf](http://www.who.int/mental_health/publications/whoqol_hiv_bref.pdf)

iv. WHO-DAS

<http://www.who.int/classifications/icf/whodasii/en/>

**d. Cognition**

i. MoCA (Montreal Cognitive Assessment): [www.mocatest.org](http://www.mocatest.org)

ii. International HIV Dementia Scale.

<https://www.hiv.uw.edu/page/mental-health-screening/ihtds>

**e. Depression, Anxiety and Other Mental Health Issues**

i. Administering the Patient Health Questionnaires 2 and 9 (PHQ 2 and 9) in Integrated Care Settings:

[https://www.health.ny.gov/health\\_care/medicaid/redesign/dsrp/docs/2016-07-01\\_phq\\_2\\_and\\_9\\_clean.pdf](https://www.health.ny.gov/health_care/medicaid/redesign/dsrp/docs/2016-07-01_phq_2_and_9_clean.pdf)

ii. Five-Item Geriatric Depression Scale:

[http://sagelink.ca/sites/default/files/clinical-resources/geriatric\\_depression\\_scale\\_5\\_item.pdf](http://sagelink.ca/sites/default/files/clinical-resources/geriatric_depression_scale_5_item.pdf)

iii. PHQ Screeners. This site offers screening tools for depression and anxiety in multiple languages. It is industry-sponsored, however:

<http://www.phqscreeners.com>.

iv. \*SAMHSA (Substance Abuse and Mental Health Services Administration) HIV and Aging Toolkit:

<https://hivmentalhealth.edc.org/toolkits/hiv-and-aging-toolkit>

f. **Loneliness.** The Campaign to End Loneliness suggests several relevant and simple tools:

<https://www.campaigntoendloneliness.org/frequently-asked-questions/measuring-loneliness/>

**g. Pain**

i. \*2017 HIVMA of IDSA clinical practice guideline for the management of chronic pain in patients living with HIV (Bruce et al). CID 65: e1-7.

<https://doi.org/10.1093/cid/cix636>

ii. Scope of Pain (Boston University):

<https://www.scopeofpain.com/tools-resources/>

iii. Agency Medical Director's Group of the State of Washington pain assessment tools:

<http://www.agencymeddirectors.wa.gov/AssessmentTools.asp>

#### **h. Nutrition**

- i. Nutrition Screening Initiative's DETERMINE Checklist (multiple languages): <http://nutritionandaging.org/toolkit-the-nutrition-screening-initiatives/>
- ii. Food Security Screening and Referral Toolkit (AARP Foundation/IMPAQ): [http://www.aarp.org/content/dam/aarp/aarp\\_foundation/2016-pdfs/FoodSecurityScreening.pdf](http://www.aarp.org/content/dam/aarp/aarp_foundation/2016-pdfs/FoodSecurityScreening.pdf)

#### **i. Driving**

- i. CDC site on Driver Safety: [https://www.cdc.gov/motorvehiclesafety/older\\_adult\\_drivers/index.html](https://www.cdc.gov/motorvehiclesafety/older_adult_drivers/index.html)
- ii. Older Drivers (NHTSA): <https://www.nhtsa.gov/road-safety/older-drivers>
- iii. Clinician's Guide to Assessing and Counseling Older Drivers (NHTSA, US DOT, AGS): [https://www.nhtsa.gov/sites/nhtsa.dot.gov/files/812228\\_cliniciansguidetoolderdrivers.pdf](https://www.nhtsa.gov/sites/nhtsa.dot.gov/files/812228_cliniciansguidetoolderdrivers.pdf)

#### **j. Frailty**

- i. \*Faces of Frailty in Aging with HIV Infection (Thurn & Gustafson, 2017) Curr HIV/AIDS Rep. 14:31-7. <https://doi.org/10.1007/s11904-017-0348-x>
- ii. *Frailty Consensus: A Call to Action* (Morley et al, 2014). This review offers multiple validated screening tools. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4084863/>

#### **k. Falls/Gait**

- i. National Council on Aging Falls Prevention Resources: <https://www.ncoa.org/healthy-aging/falls-prevention/>
- ii. CDC STEADI program assessment tools, patient education and referral: <https://www.cdc.gov/steady/materials.html>
- iii. CDC STEADI program tools for patient education and referral: <https://www.cdc.gov/steady/patient.html>

#### **l. Delirium**

- i. Hospital Elder Life Program (multicomponent program to help prevent delirium in the hospital): <http://www.hospitalelderlifeprogram.org>
- ii. ANA Delirium Resource Website: <http://www.nursingworld.org/MainMenuCategories/ThePracticeofProfessionalNursing/Delirium/Resources.html>

- iii. ICU Delirium and Cognitive Impairment Study Group:  
<http://www.icudelirium.org/non-icu.html>

**m. Sexual Dysfunction**

- i. \*Santi D, Brigante G, Zona S, Guaraldi G, Rochira V. Male sexual dysfunction and HIV--a clinical perspective. Nat Rev Urol. 2014 Feb;11(2):99-109. doi: 10.1038/nrurol.2013.314. PMID: 24394405.
- ii. \*Sexual Health in HIV and Aging:  
<http://hiv-age.org/2014/07/16/sexual-health-hiv-aging/>
- iii. \*ACRIA - Older Adults and Sexual Health: A Guide for Aging Services Providers.  
  
<https://aging.ny.gov/nysofa/Older%20Adults%20Sexual%20Health%20Guide%202017%20WEB%20version.pdf>
- iv. Mayo Clinic: Sexual Health and Aging:  
<http://www.mayoclinic.org/healthy-lifestyle/sexual-health/in-depth/sexual-health/art-20046698>

**n. Incontinence**

- i. Clinical Practice Guidelines (nonsurgical)
- ACP – Female Urinary Incontinence:  
<http://annals.org/aim/article/1905131/nonsurgical-management-urinary-incontinence-women-clinical-practice-guideline-from-american>
  - European Association of Urology Incontinence Guidelines:  
[https://www.europeanurology.com/article/S0302-2838\(18\)30002-2/fulltext](https://www.europeanurology.com/article/S0302-2838(18)30002-2/fulltext)
- ii. Patient Resources
- National Association for Continence: <https://www.nafc.org>
  - Simon Foundation: <http://simonfoundation.org>
  - Urology Care Foundation:  
<http://www.urologyhealth.org/educational-materials>
  - Kegel exercises:  
<https://medicine.umich.edu/sites/default/files/content/downloads/kegel-exercises.pdf>



- Bladder training: <https://familydoctor.org/bladder-training-urinary-incontinence/>

## IX. General Resources

- \*Quick Reference Guide from the New York State Department of Health and AIDS Institute:  
<http://cdn.hivguidelines.org/wp-content/uploads/20160815142103/hiv-in-older-adults.pdf>
- \*HIV-age <http://hiv-age.org/> This website has posted clinical recommendations from the HIV and Aging Consensus Project. Scroll to the bottom of the page for updates:  
<http://hiv-age.org/clinical-recommendations/>
- \*HIV and Aging Educational Videos (AETC HIV and Aging Workgroup):  
<https://aidsetc.org/toolkit/aging/videos>
- \*Uncharted Territory: A Report into the First Generation Growing Older with HIV (Terrence Higgins Trust):  
[http://www.tht.org.uk/~media/Files/Publications/Policy/uncharted\\_territory\\_final\\_low-res.pdf](http://www.tht.org.uk/~media/Files/Publications/Policy/uncharted_territory_final_low-res.pdf)
- \*Singh et al. From One Syndrome to Many: Incorporating Geriatric Consultation into HIV Care. Clin Infect Dis. 2017 Apr 6. doi: 10.1093/cid/cix311. PMID: 28387803. A review examining the role of geriatricians in HIV care.

## X. Community Resources

- Eldercare Locator: [www.eldercare.gov](http://www.eldercare.gov)
- National Council on Aging Resources for Professionals:  
<https://www.ncoa.org/for-professionals/>
- Senior Community Service Employment Program:  
<https://www.doleta.gov/seniors/>
- Federal Benefits Finder Website for the Public: <https://www.benefits.gov/>

## XI. Smartphone Applications

- \*University of Liverpool HIV Drug Interaction Checker (also online):  
<http://www.hiv-druginteractions.org/>
- \*Veterans Aging Cohort Study (VACS) Prognostic calculator:  
<https://vacs-apps2.med.yale.edu/calculator>

- c.** Alzheimer's Association Pocketcard app (covers screening, behavioral management, patient resources, driving safety and links to clinical studies):  
[https://www.alz.org/professionals/healthcare-professionals/clinical-resources/physician\\_pocketcard\\_app](https://www.alz.org/professionals/healthcare-professionals/clinical-resources/physician_pocketcard_app)
  
- d.** Safe Older Drivers (AGS)  
<https://geriatricscareonline.org/ProductAbstract/safe-older-drivers-mobile-app/B035#>