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Standard 7 HIV across the life course: Palliative Care

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Declaration of interests

• No completing interests to declare
Rationale: why a standard for palliative care

• ART extends life- but not indefinitely
• Mortality is higher among PLWH for all causes in UK (Lancet Public Health 2017)
• Cancer
  – leading cause of death among PLWH (Lancet 2014)
• Cardiovascular disease higher prevalence (CIHA 2017)
  – Over 50’s ≥3 comorbidities by 2030 (largely CVD) (Lancet Infect Dis 2015)
• Older PLWH in UK
  – HIV skills, coordination, confidentiality (IJSA 2017)
Better (palliative) care

• “improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” WHO

• “whole-person” or “person-centred” approach

• integrated early alongside disease-oriented treatments
  – in face of clinical uncertainty
  – allows individuals to make choices in advance

• Essential component of health systems and delivery
Highlights from the new Quality Statements

• Communication
  – Information should be shared in a manner at pace in line with patient preference
  – Communication should be recognised as an ongoing process as needs, preferences and priorities change
  – The specific information that has been shared should be recorded to ensure the whole team understand patient insight

• Timeliness
  – Clinical uncertainty should be recognised (i.e. treatment, prognosis or recovery are complex or unpredictable)
  – Palliative care should be included as part of whole patient management from the point of diagnosis of a life-limiting condition
• Management
  – All clinical staff should be able to provide basic assessment and delivery with respect to palliative care
  – Relationships should exist between HIV teams and specialist palliative care teams who can manage apparently refractory problems
  – Complex pain cases should be referred to a pain clinic
  – Assessment and monitoring of person-centred outcomes should underpin routine practice
  – Pain and symptom control should be at the heart of care plans and delivery
  – Palliative rehabilitation should be provided to optimise engagement, function and performance

• Planning
  – Practice will require plans to be in place for exacerbations, palliative care emergencies and when an unplanned admission is a potential risk against individual wishes
“Now is the time to look forward and plan how to die well. It should not only be with dignity and respect, but with self-knowledge too”

Roy Trevelion, HIV i-base