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# Integrating palliative care into HIV services

A practical toolkit for implementers



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## NOTE



For further information regarding what can be found on the CD-ROM, please refer to the back of this document.

  
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The purpose of this toolkit is to provide HIV care and treatment programme managers and clinicians with practical steps on how to integrate palliative care into adult and paediatric HIV services.

This toolkit:

- reviews the many benefits of integration for the patient and health system

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- presents key issues to consider when planning for integration

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- offers clear, succinct ways to initiate and sustain integration

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- provides clinical and organisation tools to guide integration

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- contains a list of helpful resources at the end of each section and on the accompanying CD-ROM.

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High-quality and efficient HIV care and treatment is the goal of every clinician and health manager. This toolkit provides a roadmap to enable implementers to achieve this aim rapidly and without significant time or expense.

The toolkit is divided into five sections:

### **Section 1:**

Defining HIV palliative care integration: What does it mean?

### **Section 2:**

What difference does HIV palliative care integration make to patients, healthcare workers and the health system?

### **Section 3:**

The what, when and where of palliative care: this section outlines the essential components of palliative care, when it should be provided and where it can be offered.

### **Section 4:**

Making it happen: Five key steps for integration for health managers and clinicians. This section offers a step-by-step guide of how service providers and managers can offer palliative care within HIV services including examples from different care settings.

### **Section 5:**

Examples of integrated palliative care in different care settings.

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# Background

## The HIV epidemic: Three decades on

Three decades into the HIV epidemic, a number of critical advances have been made in care and treatment. Combination anti-retroviral therapy (ART) now reaches nearly half of those eligible, resulting in dramatic reductions of illness and death (*WHO 2011*). People with HIV are living longer than ever before, and are able to establish families, work and lead normal lives.

Even with these tremendous gains, people living with HIV (PLHIV) continue to need help with the management of pain and other symptoms caused by opportunistic infections, medication side effects, aging and co-morbidities, such as cancer (*Chu and Selwyn 2011*). They also face depression, anxiety and other psychosocial or spiritual problems that can affect their quality of life and overall physical wellbeing, as well as their ability to adhere to treatment and to stay in care (*Bader et al 2006; Berg et al 2009; Etienne et al 2010; Horberg et al 2008; Lima et al 2007; Nakimuli-Mpungu et al 2011; Pence et al 2009; Villes V et al 2007*).

Studies suggest that at any given time 50% or more of patients presenting in an HIV clinic will require palliative care (*Collins and Harding 2007; Green et al 2010*). The type and intensity of palliative care needs will differ between those who are first diagnosed, those who are pre-ART and PLHIV who are on ART or living with AIDS (*Simms et al 2011*).

In a busy clinic environment, physical and psychosocial symptoms are not always as well managed as health care workers would like. This may be due to lack of training, medicines or support from managers to include palliative care in routine HIV care.

Increasingly, healthcare workers, people living with HIV and development partners are working to ensure that greater focus is placed on the ‘care’ in HIV care and treatment services. They are training HIV healthcare workers in palliative care, ensuring better screening and management of patient pain and other symptoms, identifying mental health morbidity and social problems, and providing the basic medicines and tools needed by clinics to deliver the care (*Downing et al 2008; FHI 360 2009, Green et al 2010; Ruiz and Cefalu 2011*).

The World Health Organization (WHO) defines palliative care as an approach aimed at alleviating the physical, psychological, social and spiritual suffering of those with life-threatening illness (such as HIV and cancer) from the point of diagnosis onwards:

***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, assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” World Health Organization (WHO), 2002***

In a recent review, 156 countries were found to have some level of palliative care service available, 45 of which (primarily developed countries) had fully integrated it into their healthcare system (*Lynch et al 2011*).

Integrative health approaches are now more critical than ever. The United Nations HIV/AIDS Investment Framework calls for greater efficiencies, better prioritisation and increased government financial contribution to basic programme activities, including HIV care and support (*UNAIDS 2011*). This toolkit provides important practical tools on how to maximise HIV care efficiencies and better utilise existing resources.

# Section 1

## Defining HIV palliative care integration

### KEY POINTS



- Integration is about providing holistic yet cost-efficient care to patients
- There are both benefits and challenges of integration
- There are different forms of integration
- Integration is achievable!

### Defining integration

The aim of integration is to enable people living with HIV to access different but connected health and psychosocial care services from one point of access, rather than via many fragmented services and providers. By doing this, HIV healthcare workers are better able to improve patient outcomes with efficiency for both the client and the healthcare system.

The World Health Organization (WHO) strongly urges health managers and clinicians to adopt integrative approaches to service delivery, particularly at the primary and secondary service delivery levels, in order to maximise holistic patient centred-care and cost-efficiency (WHO 2008). An integration pioneer at the WHO, Jan Stjernswärd, began calling for palliative care integration in the early 1990s (Stjernswärd 1996).

Here are three different, but equally valid ways in which integration has been described. The first is from the health care system vantage point. The second looks at palliative care from a patient-centered care perspective, and the third from the client's perspective following successful implementation:

***“Integration is the organization, coordination, and management of multiple activities and resources to ensure the delivery of more efficient and coherent services in relation to cost, output, impact and use [of health services]”***  
(WHO 2011).

***“An organisational process of coordination which seeks to achieve seamless and continuous care, tailored to the patients’ needs and based on a holistic view of the patient”***  
(Mur-Veeman et al 2003).

***“People get the care they need, when they need it, in ways that are user-friendly and that achieve the desired results and provide value for money.”***  
(WHO 2008).



## Benefits and challenges of integration

Studies have identified measurable benefits of integration at a health system and patient level (*Atun et al 2010; Kennedy et al 2011; WHO 2008*). These include:

- services that are better coordinated and less fragmented
- cost savings and efficiencies due to improved coordination and synergies
- higher use of services, better coverage and therefore increased client access to services at each point of contact
- increased quality care and, as a result, better patient outcomes.

While the overall results of integration are many and predominately positive, there are, of course, challenges. The decision to integrate services means factoring in time to train, mentor and guide healthcare workers in new skills (eg. management of pain). If patients perceive improvements in the quality of their care, there may also be increased demand for services, which can have an impact on staffing and projections for medicines needed. However, most of these challenges can be overcome by starting small and planning ahead.

## Different degrees of integration

Integration can range from a robust referral system between a clinic and a local palliative care service, to complete integration of palliative care in HIV services through training HIV clinicians, enhancing screening practices for palliative care needs, and ensuring basic medicines are available (*Atun et al 2010; Green 2010*).

### APPENDIX



Appendix 1: Types of HIV palliative care integration.

## Section 2

# What difference does the integration of palliative care into HIV services make to patients, health care workers and the health system?

### KEY POINTS



- Pain and other symptoms are linked with poor quality of life and reduced adherence to ART
- Integration of palliative care into HIV services results in better health and emotional wellbeing for people living with HIV (PLHIV)
- Palliative care can be integrated in HIV outpatient care, inpatient services, home-based care and closed settings.

The integration of palliative care into HIV services is very important for improved patient wellbeing and better service delivery. Here is why:

### **Pain and other symptoms cause physical and psychological suffering and reduced wellbeing**

In recent studies in Africa, Asia and elsewhere, PLHIV primarily on combination antiretroviral therapy (ART) reported experiencing an average of 8-18 symptoms at any one time, with the majority reporting at least one symptom (*Harding et al 2010; Green et al 2012a; Lee et al 2009*).

These symptoms can translate into physical and emotional distress and reduce quality of life (*Bader et al 2006; Green et al 2012b; Harding et al 2006*).

### **PLHIV with pain, fatigue and other symptoms are much less likely to be adherent to ART**

A number of studies have shown that the greater the number and the more severe symptoms that PLHIV report, the lower their ART adherence levels are (*Ammasarri et al 2001; Berg et al 2009; Gay et al 2011; Heath et al 2002*).

Some symptoms (such as fatigue and difficulty concentrating) result in lower adherence, while poor adherence can also lead to an increase in the prevalence and severity of symptoms (*Gay et al 2011*).

### **Depression, anxiety and lack of social support are linked with poor health, loss to follow-up and reduced adherence to ART**

PLHIV who are depressed are less likely to be adherent to ART than those who are not (*Horberg et al 2008; Nakimuli-Mpungu et al 2011*). They are also prone to missing appointments and dropping out of care once they are enrolled (*Gonzalez et al 2011; Holzemer 2002; Johnson et al 2008*). But PLHIV who receive mental health support are more likely to seek HIV treatment and remain adherent to it (*Barton et al 2005; Horberg et al 2008; Yun et al 2005*).

Because of the interconnection between mental health and physical health, PLHIV with depression are at an elevated risk of HIV disease progression and death (*Antelman et al 2007; Leserman 2008; Villes et al 2007*).

### **As PLHIV age they face more health problems that threaten their well-being**

As PLHIV age, their risk of dementia, bone deterioration, non-AIDS related cancers and organ-related diseases increases. Overall, PLHIV are significantly more likely to develop these diseases than people in the general population and to develop them earlier in life (*Guaraldi et al 2011a, b*).

For example, while AIDS-defining cancers have decreased over the past decade, cancers not associated with AIDS such as prostate, colon and liver cancer have increased three-fold (*Shiels et al 2011*). Neurocognitive disorders, including dementia, affect up to 50% of PLHIV on ART (*Heaton et al 2010*).

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### **Active symptom screening may be an efficient way of identifying poor immune function and treatment failure**

Where HIV clinics routinely ask patients about symptoms, they may be better able to identify those at risk of viral rebound and use this information to make decisions regarding treatment durability (*Lampe et al 2010*).

Evidence indicates that when HIV programmes integrate symptom management or other elements of palliative care as part of routine services, PLHIV:

- experience fewer and less distressing physical symptoms (*Green 2012b*)

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- are more adherent to ART (*Chiou et al 2006*)

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- have better immune function and reduced mortality (*Chiou et al 2006; Kabore et al 2010; Zachariah et al 2007*)

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- are more likely to stay in care (*Etienne et al 2007*)

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- have fewer psychological problems (*Green 2012b; Selman et al 2008*)

---

- have better overall quality of life (*Chiou et al 2006*).

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HIV clinic and other healthcare workers involved with integrating palliative care, report greater satisfaction in clinical care and better relationships with patients. One doctor in Vietnam reported:

***“I think patients feel much more comfortable with me. They answer with ease whenever I ask them questions. They are also not hesitant to ask me questions. In general, it is quite a good atmosphere in the clinic and my consultation room now.” (Green 2012c).***

At the health systems level, studies have shown palliative care integration into hospital services can lead to significant cost savings (*Morrison et al 2008*).

It does this through identifying physical and psychosocial problems earlier and reducing the need for hospitalisation. Better ART adherence and retention in care also means that PLHIV stay on more affordable regimens for longer and experience less viral resistance.

So what can happen when services are not well integrated?

***“Lack of integration can result in late referrals, unnecessary delays for treatment, transfer to an inappropriate setting of care, unnecessary suffering and cost.” (Dudgeon et al 2007).***

## Section 3

# The 'what', 'when' and 'where' of HIV palliative care

### What elements of palliative care should be offered to people living with HIV?

In practical terms, integrating palliative care means 'adding' it to the existing clinical skills of health care workers, providing clinical assessment tools and securing medicines to support its application, and further developing referral services to ensure patients with, for example, psychiatric issues that the HIV service feels it cannot address, are transferred to a trusted partner.

For an HIV/ART clinic, infectious disease ward or home-based programme that decides to incorporate palliative care into its service, the 'essential' components of care are:

- the assessment of patient/family physical, emotional, social, and spiritual needs. This includes:
  - screening for pain and other physical symptoms (including side effects of ART)
  - screening for mental health and social support needs

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- treating symptoms based on findings using available medicines

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- addressing mental health and social support needs based on the capacity of the service

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- discussing self-care skills and longer-term care needs with the client

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- providing follow-up and making referrals where required.

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Table 1 (opposite) provides an illustrative list of palliative care components that can be integrated into HIV services. The type and focus of an HIV service will determine the extent to which each of the items in Table 1 will be addressed. For example, if oral morphine will take time to secure or may not be possible to obtain at all, a service should do the best they can using available medicines to treat pain, and where available, refer the client for more advanced pain management. Similarly, a busy HIV/ART clinic may not have

the time or expertise to offer spiritual counselling, but if a client states this as a need, they can be linked with a local service that can provide support in this area. The key is to have a functional referral system in place.

Palliative Care	Interventions
<b>General</b>	<ul style="list-style-type: none"> <li>• Clinical or lay assessment of physical, emotional, social and spiritual needs of the patient and his/her family</li> <li>• System of referrals to link clients to services which can help address problems identified.</li> </ul>
<b>Physical</b>	<ul style="list-style-type: none"> <li>• Assessment, prevention and treatment of pain</li> <li>• Assessment, prevention and treatment of other symptoms</li> <li>• Assessment and treatment of medication side-effects (eg. ART, TB treatment, cotrimoxazole prophylaxis, morphine)</li> <li>• Teaching self-care to manage symptoms and side-effects in the home and recognise danger signs</li> <li>• Attending to physical needs at the end of life.</li> </ul>
<b>Emotional</b>	<ul style="list-style-type: none"> <li>• General counselling and emotional support</li> <li>• Treatment of psychiatric problems (eg. depression, anxiety)</li> <li>• Self-help groups</li> <li>• Care of caregivers (lay and professional providers and family), eg. through support groups, counselling</li> <li>• Bereavement support, eg. counselling to help families with grief and future planning.</li> </ul>
<b>Social</b>	<ul style="list-style-type: none"> <li>• Help with managing stigma and discrimination</li> <li>• Support with legal issues (eg. preparing a will)</li> <li>• Assistance with financial and other material needs (eg. nutrition, housing and education).</li> </ul>
<b>Spiritual</b>	<ul style="list-style-type: none"> <li>• Spiritual counselling</li> <li>• Life review counselling</li> <li>• Funeral and other life completion tasks.</li> </ul>

Table 1: Example of Palliative Care Services

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## When should palliative care be offered to people living with HIV?

PLHIV require palliative care from the time they receive their HIV diagnosis – and studies show this is a period of acute need – and during the period prior to starting ART when they may experience a number of psychological symptoms as a result of coping with their disease, along with physical suffering due to opportunistic infections, inflammation caused by HIV, or co-morbidities.

PLHIV who are just starting ART will need help with managing side-effects, while PLHIV who have been on ART for a number of years will need help with long-term side-effects, co-morbidities and diseases related to HIV induced premature aging.

## Where are palliative care services needed?

PLHIV and their families require a continuum of prevention and care, where their needs are addressed by a network of providers over time. This is why a primary component of palliative care integration is strengthening and expanding existing referral networks. Care can be provided by existing health services such as HIV outpatient clinics, inpatient wards, community and home-based care, day care, or hospices. It can also be provided in prisons to patients who have been incarcerated.

Figure 1 (opposite) reflects both the cross-cutting nature of palliative care and its application across the continuum of prevention and care.



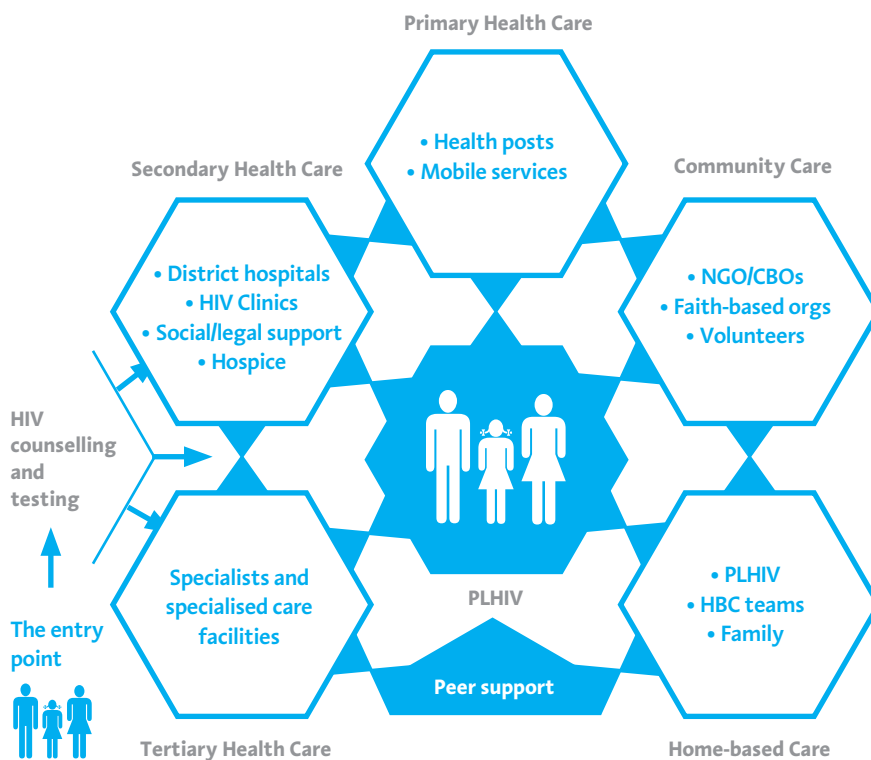


Figure 1: Continuum of prevention and care

Chart source: Green K et al 2007. Adapted from Narain JP, Chela C and van Praag E. Planning and implementing HIV/AIDS care programmes: a step by step approach. New Delhi, WHO Regional Office for South-East Asia, 1998.

## FURTHER READING



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## CD-ROM



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## Section 4

# Making it happen: steps to integration

### What elements of palliative care should be offered to people living with HIV?

CD-ROM



CD-ROM 1: Palliative care associations and online resources.

This section provides both health managers and clinicians with information and tools for integrating palliative care into HIV clinical services based on the experience of HIV clinics across Africa and Asia (*FHI 2009*). It focuses on five key steps that can be applied by service implementers, such as heads of HIV clinics, home-based care programme managers or inpatient care directors, to make palliative care services available.

There is no right or wrong model of palliative care integration. Each service or programme will need to adapt the steps described in this section according to what makes the most sense in their operating environment. This section recognises that integration is a process and that services will need to 'build the ship while sailing it'. Some steps such as training can be done relatively quickly, while others, such as securing oral morphine, might take more time. HIV clinics and other HIV service providers who successfully integrate palliative care generally followed the below five key steps shown in Figure 2 (opposite).

Before getting started, it is very helpful to meet with local palliative care providers to see how they might be able to help support the integration effort. They may be able to offer training, mentoring, advice on how to access opioids and other palliative care medicines, and be prepared to receive referrals for individuals with complex needs.



Figure 2: The HIV palliative care integration process: five key steps

## KEY POINTS



- Form an integration team
- Identify and assess palliative care-related gaps and opportunities
- Create awareness and commitment for palliative care integration.

## Step 1: form a team and assess opportunities and gaps in integration

### Form an integration team

Whether you work at an HIV clinic, manage home-based care services or run an inpatient ward in the hospital, putting together a small team is the best way to initiate the integration process. The team will often include the clinic director, clinicians, home-based care team representatives (where they exist) and PLHIV clients. The key is to involve those who can ensure that the integration process is appropriate and efficient, without overwhelming too many people with additional work.

The team's primary aim is to assess palliative care needs of clients and decide what steps will be required to incorporate services to address these needs. It will then guide and monitor the implementation of services.

The way in which the team is formed will vary from setting to setting. In Ho Chi Minh City, Vietnam, for example, a primary need identified was access to oral morphine to treat pain. In order to ensure the acceptability of this intervention, the provincial AIDS committee and provincial health service established a city-level technical working group and hospital HIV clinic level teams. This approach resulted in official support for palliative care integration efforts (Vu et al 2011).

In other countries, the planning team has been less formal and organised at the service level. For example, in Uganda, palliative care was integrated into HIV clinical and home-based care services by training and certifying staff to lead the integration process within their own services (Downing et al 2008; Downing et al 2010).

## Identify and assess palliative care-related gaps and opportunities

The purpose of this assessment is to ascertain priority palliative care needs among clients and families, and to identify where there are gaps and opportunities in current service delivery based on the needs identified.

There are a number of ways that PLHIV palliative care needs and HIV service capacity can be assessed. These are described briefly below. In addition, the integration team may want to rapidly map related services (eg. for referral) and review the local, regional or national policy setting so that they are aware of any existing facilitators or barriers to palliative care integration.

### Client needs assessment

PLHIV palliative needs can be determined through a combination of objective and subjective methods depending on time and preference, for example, by using a screening tool and/or through focus group discussions or one-on-one interviews.

To measure palliative care needs, a clinic or home-based care assessment can be conducted – where all clients receiving care that day (or over a few days) are asked to respond to questions from a short assessment tool. The Palliative Care Outcome Scale (POS), the MOS-HIV or Memorial Symptom Assessment Scale (MSAS), for example, can provide information on the prevalence of symptoms (both physical and psychological), and social and spiritual needs in the patient population within the past week or month.

## APPENDIX



Appendix 3: Guide to palliative care screening and assessment tools.

These results, especially for physical symptoms, can be compared to clinical records to identify how well clinicians are detecting symptoms.

This type of rapid clinical census provides useful information on patient needs and how well they are currently being addressed.

Asking PLHIV and their families about their physical, psychological, social and spiritual wellbeing can also reveal meaningful information about how they perceive their needs and what they prioritise as important. What PLHIV and families see as critical to their quality of life may vary from what service providers think is important. A good way to approach these interviews is by organising a focus group discussion with PLHIV leaders, who are comfortable in expressing their opinions and are knowledgeable about the needs of other PLHIV attending the service.

#### Service capacity assessment and medicine audit

Review HIV service capacity by conducting a SWOT exercise (analysis of HIV service Strengths, Weaknesses, Opportunities and Threats) in relation to palliative care integration.

Questions that might be asked include:

- Is the service adequately addressing the most prevalent needs cited by clients?

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- How well are clinicians detecting symptoms reported by clients during the assessment?

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- How strong is client-provider communication?

---

- Are the physiological, social and spiritual needs of clients adequately assessed and responded to?

---

Assess the training and capacity needs of service staff. Questions that might be asked include:

- Have they ever been trained in palliative care, mental health or communication skills?

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- What did the training involve?

---

- Based on the PLHIV needs assessment, are there any areas of training that are specifically required?

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Conduct a review of medicine availability. This simply involves comparing medicines currently available through the service to those that are important in symptom management (eg. opioids to treat pain or amitriptyline to manage neuropathy).

The Basic palliative care medicine list in Appendix 5 can be used as a checking aid.

### Service mapping

Compile a list of identified resources, contact information, details on services and fees. No HIV service can do it all, so it is important to know what resources are available and how referrals can be made to them.

Examples of essential referral sites are those that are able to manage complex symptoms (eg. pain that will not respond to routine treatment), severe mental health problems and specific social problems (eg. housing, food supplementation and welfare), or provide end-of-life care for those with treatment failure.



## POLICY REVIEW

- Q Is there a national palliative care policy or guidelines?

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- Q Does the national health plan include palliative care?

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- Q Is there an essential medicines list that includes medicines for palliative care?

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- Q Do national policies address opioid prescribing rules and systems for distribution and dispensing of medications?

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### Policy review

Conduct a rapid policy review (if there is time available). This review will enable the team to determine whether or not there are laws or regulations enabling or preventing palliative care integration. For example:

- Are there national palliative care guidelines?

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- Are palliative care medicines part of the national essential drug list?

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- Are HIV clinics able to access and prescribe oral morphine?

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See ‘Further reading’ opposite, for examples of tools used in palliative care policy reviews.

### Create awareness and commitment for palliative care integration

Once information is available on patient and family palliative care needs, levels of existing palliative care training and medicines available and the opinions of leaders, the assessment can be presented to key decision-makers.

In Papua New Guinea, once a needs assessment for the integration of palliative care into home-based care services was completed by FHI 360, meetings were held with the national HIV programme, with local health and social welfare leaders, and with religious, PLHIV and community members. The media were also invited to participate in some of the meetings to promote greater awareness of the palliative care needs of PLHIV.

At each of these meetings, feedback was sought on what steps should be taken to better address the palliative care needs of PLHIV. This formed the basis of the final HIV palliative care integration plan (see Step 2).



## FURTHER READING



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## Step 2: Develop an integration plan



- Develop a plan with clear activities, time frame and responsibilities
- Validate the integration plan with key stakeholders.

### Develop a plan with clear activities, time frame and responsibilities

The aim of the integration plan is to provide the integration team with a clear pathway of the steps needed to make palliative care available to clients. The plan should be developed collaboratively with those involved in the assessment and other key stakeholders. (See Figure 3 for an example of useful workplan format.) A good plan specifies what needs to be done, when, and by whom. It also specifies what can be done in the immediate, intermediate and long-term. For example, incorporating a screening tool such as the Palliative Care Outcome Scale (POS) can be done relatively rapidly, while procuring oral morphine may take longer.

Activity	Who is responsible	Time frame				Cost	Total	Target Expected output
		O1	O2	O3	O4			

Figure 3: Sample format for palliative care integration workplan

Source: Green K, McPherson R, Loy R, Masami F, Chawalit N, Gulaid L, van Praag E. *Scaling up the continuum of care for people living with HIV in Asia and the Pacific: a toolkit for implementers*. Bangkok, Thailand: FHI; October 2007.

### Validate the integration plan with key stakeholders

A draft plan should be shared with others to seek feedback on whether the plan resonates with needs assessment findings and to solicit new ideas and information. The validation process is also a way of increasing buy-in and support for the integration effort.

Who is involved in validating the plan depends on local needs and the level of advocacy required. In some cases, a small meeting with the hospital and perhaps key local referral sites can be arranged and will be sufficient; in others cases, large-scale validation may be necessary.

In South Africa, for example, the plan for an integrated community palliative care project involved planning at national, provincial and district levels. The National Department of Health identified the two pilot sites, and representatives from those Districts then formed a multidisciplinary team, which included leadership from community care groups and ART clinic supervisors. Each stakeholder had a role to play in implementing the project after the initial programme design discussions.

Project leaders from the clinics and organisations met with their staff to introduce the project and gain support. A palliative care training schedule and trainers were arranged for all members of the interdisciplinary team by the project coordinator. The team responsible for managing the integration effort met to monitor progress on the workplan and address barriers to the successful execution of the plan (*FHI 360, 2009*).

CD-ROM



Green K, McPherson R, Loy R, Masami F, Chawalit N, Gulaid L, van Praag E. — 'Scaling up the continuum of care for people living with HIV in Asia and the Pacific: A toolkit for implementers.' Bangkok, Thailand: FHI 360; October 2007

[www.fhi360.org/en/HIVAIDS/pub/res\\_CoC\\_toolkit.htm](http://www.fhi360.org/en/HIVAIDS/pub/res_CoC_toolkit.htm)

## KEY POINTS



- Integrate palliative care roles into staffing structure
- Train clinicians and other care providers
- Secure key medicines
- Adapt and use clinical tools to assess symptoms and other palliative care needs
- Develop referral mechanisms
- Integrate palliative care into existing patient information monitoring systems.

## Step 3: build systems and skills to support palliative care integration

This section provides information on the key steps required to start up palliative care services. Not all these steps need to be conducted in the order they are listed; they can take place in whatever order makes the most sense for any given HIV service. In practice, many of these steps will occur simultaneously.

### Integrate palliative care roles into staffing structure

Review current job functions within the HIV service and identify what members of staff will be doing in relation to palliative care once trained. For example, HIV nurses may be involved with symptom screening, while doctors will assess and treat presenting symptoms. Existing ART adherence counsellors or case managers can be trained to provide a greater range of emotional support to clients, including screening them for mental health morbidity, providing counselling and referrals where needed. HIV doctors will generally focus on assessment and prescription of medicines for the management of depression, anxiety and dementia.

At the end of this step, there should either be revised job descriptions which include these roles, or other steps should have been identified to ensure that expectations around palliative care functions are clear to all members of staff.

### Train clinicians and other care providers

Since palliative care may be new to healthcare workers in an HIV service, the first step will be to train them in the basics. Basic training can usually be done in a day or less, and should provide information on:

- why palliative care is important to the quality of life of PLHIV and their families
- the prevalence of pain, other symptoms and mental health illness in PLHIV
- key interventions within HIV services that can be implemented to address these problems.

***In Zimbabwe, Island Hospice Service Harare provided palliative care awareness sessions for all staff members at Chitungwiza Hospital at the initial stage of the project. This proved to be very helpful to the palliative care providers who then could count on the support of hospital staff.***

## FURTHER READING



See 'Further reading' on page 35 for sample training tools.

It is generally helpful to invite managers and other individuals, who are not be involved in the day-to-day operations of the HIV service, as their support is vital. This may be a hospital director, head of pharmacy or head of an NGO. Try working with a local palliative care service provider who can support the HIV service in planning and running the training.

Staff who will be more involved in the delivery of palliative care will require more in-depth training and clinical placement. These courses are usually a minimum of five days and often longer to include time for practical application of skills. Since it may be difficult for busy healthcare providers to leave work for more than one week for training, a series of shorter sessions could be held to ensure the fundamentals of HIV clinical palliative care are understood. These trainings can be interdisciplinary where doctors, nurse, pharmacists, and psychosocial support workers (eg. counsellors, social workers, case managers or peer supporters) are trained together.

In addition to classroom and practical training, periodic mentoring can be very helpful in building and enhancing learned skills. In some countries, HIV clinics have utilised local palliative care clinicians or mentoring programs to provide mentoring. One or two people per HIV service can also mentor and support palliative care skills development in other members of their team.

## APPENDIX



Appendix 5: Illustrative list of basic palliative care medicines. See CD-ROM 4 also.

### Secure key medicines

HIV services will need to identify which medicines are required to offer a minimum level of palliative care. Usually services have basic symptom care medicines for nausea, diarrhoea and pain. These include analgesics such as paracetamol and ibuprofen. However, HIV services are less likely to have access to mild or strong opioids (eg. codeine and morphine).

Key medicines that are important for palliative care management include the following:

- Medicines for neuropathic pain, such as amitriptyline. Amitriptyline is very inexpensive and highly effective. It can also be used to treat clinical depression and anxiety
- Opioids to manage moderate to severe pain. HIV clinics and home-care services wanting to offer palliative care will need to explore ways in which these medicines can be made available. Codeine is sometimes available over-the-counter on its own or co-formulated with paracetamol. For stronger opioids, the preferred medicine is oral morphine, which is easy to tolerate, rapidly absorbed and very inexpensive.

HIV services should consult with palliative care providers or their national palliative care association to determine how these medicines can be included in clinical care. This may involve registering HIV physicians as narcotic prescribers with the provincial health services and using specific forms to request anticipated amounts of oral morphine.

HIV clinics in countries such as India, Kenya, South Africa, Tanzania, Uganda, Vietnam and Zambia have successfully navigated narcotic regulations to ensure oral morphine is available for PLHIV in severe pain.

## Adopt clinical tools to facilitate the integration of palliative care

### Screening and assessment tools

HIV services should adopt a basic screening tool to better detect symptoms and other palliative care needs. HIV clinicians tend to find these tools very helpful.

***“I think it [the HIV service] is much better. It is helpful that we have a set of questions to follow. Without it, we tend to forget. Now we care for clients more, not just their physical health, but also asked more about feelings, pain etc. In general, it is quite a good atmosphere in the clinic now.”***

*HIV doctor, Vietnam.*

There are many existing palliative care patient assessment tools that can be used in HIV care settings. The key is to start with short, targeted clinical assessment tools, which are feasible to use and not too long or complicated. The same instruments used during the needs assessment phase (see Step 1) can be integrated into clinical care. These include the Palliative Care Outcome Scale (POS), the MOS-HIV or Memorial Symptom Assessment Scale.

HIV services can also adapt existing tools or develop their own. In Vietnam, HIV clinics developed a short tool that captured the most common symptoms/problems they saw in their clients. The aim was to ask patients about their symptoms and to scale their severity (see Figure 4 - overleaf).

## APPENDIX



Appendix 3: Guide to palliative care screening and assessment tools (identifying which assessment tools have been validated in your country is a very useful exercise).



Symptom assessment form		
No pain ( including backache, headache)	0 1 2 3 4 5 6 7 8 9 10	Worst pain imaginable
No cough	0 1 2 3 4 5 6 7 8 9 10	Worst cough
No fatigue/tiredness	0 1 2 3 4 5 6 7 8 9 10	Worst fatigue/tiredness
No difficulty sleeping	0 1 2 3 4 5 6 7 8 9 10	Worst difficulty sleeping
No numbness, tingling or shooting pain (in legs/feet or hands/arms)	0 1 2 3 4 5 6 7 8 9 10	Worst numbness, tingling or shooting pain
No lack of appetite	0 1 2 3 4 5 6 7 8 9 10	Worst lack of appetite
No nausea/vomiting	0 1 2 3 4 5 6 7 8 9 10	Worst nausea/vomiting
No itchy skin	0 1 2 3 4 5 6 7 8 9 10	Worst itchy skin
No diarrhea	0 1 2 3 4 5 6 7 8 9 10	Worst diarrhea
No sadness/depression	0 1 2 3 4 5 6 7 8 9 10	Worst sadness/depression
No worry/anxiety	0 1 2 3 4 5 6 7 8 9 10	Worst worry/anxiety

Figure 4: Symptom assessment form (Source: Green K 2010)



Clinic staff then used a sheet to record changes in these scores over time so they could assess how well symptoms were being addressed (See Figure 5 below). These tools were added to the existing patient assessment forms and files.

Date														
Pain (including headache, backache etc).														
Cough														
Fatigue/ tiredness														
Difficulty sleeping														
No numbness, tingling or shooting pain (in legs/feet or hands/arms)														
No lack of appetite/ cannot eat														

Figure 5: Tracking symptoms over time (Source: Green K 2010)



## CD-ROM

CD-ROM 4: Pain assessment tools and questions.



## APPENDIX

Appendix 3: Guide to palliative care screening and assessment tools.

Managing pain is a particularly important aspect of palliative care. HIV clinical services should include a tool for healthcare workers to use in assessing the severity and character of pain in patients (eg. using a 0-10 scale). There are eight important questions to ask the patient:

- Where is the pain? (There may be more than one pain)
- When did it start?
- Severity: how intense is the pain now? (Measure using a pain scale)
- What does it feel like (eg. stabbing, cramping, burning, etc)?
- Timing: is the pain there all the time or does it come and go?
- Treatment: has any treatment been tried and has it helped?
- Changing: what makes it better or worse (eg. movement, eating, time of day, etc)?
- Cause: what do you (the patient) think is causing the pain?

Mental health is another very important part of palliative care, and specific tools are required to help providers to detect and respond to problems, such as depression and anxiety. To simplify screening, two questions can be used (see Figure 4), asking clients whether or not they have felt

sad or worried in the past week or month. If so, they are asked how severe these problems were on a scale of 0 to 10. Those whose score indicates a moderate or severe problem can be further assessed for depression or anxiety using a brief measure such as the Hospital Anxiety and Depression Scale (HADS).

Such a scale will indicate to the health worker whether or not their client is symptomatic of mild or more severe mental health disease.

#### Job aids and tools

ART clinics and other places where HIV care is provided tend to be busy environments. Having job aids in place can reinforce learned skills and also provide PLHIV clients with increased awareness of what types of questions/assessment their provider should offer.

For example, HIV clinicians in Vietnam developed a pain assessment poster, which was then adapted for use in Africa by the African Palliative Care Association (APCA). Clinicians in Africa and Asia have found it to be very useful. A copy can be found on the CD-ROM and it is free to be replicated for use in other settings.

#### Care plans

Care plans are simple forms that are used to detail how the patient and family's problems will be addressed (by who, how, for how long), and how patients will participate in meeting their own needs.



## CD-ROM

CD-ROM 1: Palliative care associations and online resources.

### **Develop referral mechanisms**

No one service can provide everything PLHIV and their families need at a given time, so a referral system is essential when offering palliative care. Therefore, the key step for those wanting to integrate palliative care into their services is to assess what linkages already exist with home-based care, with specialty palliative care services and with mental health and social welfare services, and to create or strengthen these links as necessary. Your national palliative care or other local palliative care service provider will be able to link you with the closest services in your area.

Representatives from key referral sites can also act as advisors in the integration process and provide training and mentoring to HIV service staff.

### **Integrate palliative care into existing patient information monitoring systems**

Palliative care services need to be recorded and tracked so HIV services are able to:

- assess the prevalence of different symptoms
- calculate the degree of symptom improvement over time
- measure palliative care medicine consumption.

At the end of each month, these three areas can be tallied and information provided to HIV service staff to enable them to make decisions about areas that might need improvement and to inform medicine procurement.

## FURTHER READING



### Training

FHI 360 — ‘HIV/AIDS care and treatment, a clinical course for people caring for persons living with HIV/AIDS.’

Washington, DC: FHI 360, 2004

[www.fhi360.org/en/HIVAIDS/pub/guide/careandtreatmentclinicalcourse.htm](http://www.fhi360.org/en/HIVAIDS/pub/guide/careandtreatmentclinicalcourse.htm)

University of Washington Center for Palliative Care Education — ‘HIV/AIDS palliative care training module.’

Seattle, WA: UW, 2006

<http://depts.washington.edu/pallcare/training/overview.shtml>

### Medicine access

International Hospice and Palliative Care Association (IAHPC) — ‘List of essential palliative care medicines.’

[www.hospicecare.com/resources/emedicine.htm](http://www.hospicecare.com/resources/emedicine.htm)

Bond C, Lavy V, Woolridge R. — ‘Palliative care toolkit: Improving care from the roots up in resource-limited settings.’

World Palliative Care Association: London, United Kingdom, 2008

<http://www.helpthehospices.org.uk/our-services/international/what-we-do-internationally/education-and-training/palliative-care-toolkit/get/>



WHO. — ‘Ensuring balance in national policies on controlled substances: guidance for availability and accessibility of controlled medicines.’

Geneva, Switzerland: WHO, 2000

<http://www.painpolicy.wisc.edu/publicat/oowhoabi/oowhoabi.htm>

### Clinical tools

FHSSA. — ‘A Clinical Guide to Supportive and Palliative Care for HIV/AIDS in Sub-Saharan Africa.’ Washington, DC: FHSSA, 2006

[www.fhssa.org/i4a/pages/index.cfm?pageid=3489](http://www.fhssa.org/i4a/pages/index.cfm?pageid=3489)

‘Memorial Symptom Assessment Scale.’

<http://www.expert-reviews.com/doi/abs/10.1586/14737167.4.2.171?journalCode=erp>

‘Palliative Care Outcome Scale.’

<http://pos-pal.org/>



## FURTHER READING



See 'Page 39' for examples of clinical care guidelines.

## Step 4: Implement integration plan in a phased approach

### Provide clinical care

Once providers have been trained and have decided on patient assessment tools to use, service delivery can begin. There are a number of palliative care guides that can be used to support clinicians in managing pain, other symptoms and mental health diseases, but each HIV service will need to follow national guidelines where they exist.

HIV services should aim to screen all clients as they are seen (eg. for their monthly clinic visit) for palliative care needs. Clinicians will need to treat identified symptoms and link patients with home-based care services for community follow-up and treatment adherence support. In very busy HIV clinics where clinicians do not always have time to use the symptom screening tool, PLHIV or other clinic staff/volunteers can screen for symptoms while clients are in the waiting room. Not all palliative care medicines will be available when services begin. This is OK. Some medicines will take longer than others to procure. In the interim, available medicines can be used and referrals made to specialists where they exist.

During the implementation phase, organise for a palliative care clinical mentor to be on call, who can answer questions and periodically provide on-site mentoring to the HIV service team.

### Respond to mental health, social and spiritual needs

It is usually relatively straightforward for HIV services to integrate the management of physical symptoms into care. It can take more time for mental health care to be incorporated. This is because many HIV service providers have not had training in mental health. The stigma often attached to mental health may also mean that health care

workers may not be aware of its importance. As a result, depression and anxiety, which are very common in PLHIV, are often hidden from view. Addressing mental health is not only critical for patients' quality of life, it is also essential for promoting retention in care, better ART adherence and physical wellbeing. Social worries (eg. about income, housing and child care) are often sources of extreme worry and anxiety, which can lead to or exacerbate underlying mental illness. Likewise, concerns about spiritual wellbeing are also commonly experienced by people with severe emotional and social suffering. Drug and alcohol abuse are common in PLHIV and critical to screen for and address; they are associated with depression, illness and death.

An increasing number of HIV services are integrating mental health care into their provision. They have done this by training and mentoring HIV counsellors and clinicians and ensuring that the essential medicines needed to treat depression, anxiety and dementia are available.

In Vietnam, three levels of prevention and care are provided: PLHIV with mild problems receive training in traditional stretching, breathing and meditation; those with moderate illness receive a form of cognitive counselling alongside the traditional treatments; while PLHIV with severe diseases generally receive treatment using anti-depressants in addition to counselling and traditional support (*AIDSTAR-One 2010; Green 2012c*).

Not all HIV services will be able to fully address mental health, social concerns and spiritual wellbeing, but they should at a minimum screen for these issues, manage non-complex mental health cases, and refer clients with complex psychiatric disorders. Home-based care teams are often better placed to meet the social and spiritual needs of clients and provide lay emotional support.

  
**NOTE**

For further information regarding what can be found on the CD-ROM, please refer to the back of this document.

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### **Promote client and family self-care skills**

Symptom management starts at home. When PLHIV and their families are knowledgeable about how to manage mild symptoms in the home and how to detect more serious symptoms, they are able to participate actively in their care. Participation in care can result in better adherence, quality of life and clinical outcomes (*Chiou et al 2006*). As part of service integration, HIV clinics can include a session on symptom identification and care in PLHIV support group meetings or in the waiting room while patients are waiting to see a healthcare worker. They can also train a local community home-based care team to teach PLHIV clients and families about symptom care during home visits. The CD-ROM includes a selection of symptom self-care handbooks that can be readily adapted to suit different contexts.

### **Incorporate palliative care into team meetings and case conferences**

Interdisciplinary teamwork is a vital component of palliative care. Palliative care should be integrated into existing clinic or hospital clinical teams. For example, it should be discussed during case conferences. Referrals to other service providers can also be reviewed, so that follow-up is a routine part of the care plan, updates and team meetings. Where linkages to home-based care teams have been made, representatives can be invited to clinic meetings to discuss referrals and findings during home visits.

### **Care of caregivers**

Palliative care providers can often encounter difficult issues in people's lives. Often these issues touch a chord in the life of the caregivers, whether they are professional, voluntary or family members. HIV services will need to consider how to provide support to their staff, if support is not already in place. Support may include de-brief opportunities to discuss an emotionally charged experience, eg. after a difficult death, or referrals to a local counsellor. The Thogomelo Project in South Africa, for example, established support groups for caregivers and an annual award ceremony to give well-earned recognition (*PATH, 2010*).



## FURTHER READING



### Clinical care guidelines and handbooks

African Palliative Care Association (APCA). — 'A handbook of palliative care in Africa.'

Kampala, Uganda: APCA, 2010

<http://www.africanpalliativecare.org/images/stories/pdf/Handbook.pdf>

African Palliative Care Association (APCA). — 'Beating pain: A pocket guide for pain management in Africa.'

Kampala, Uganda: APCA, 2010

[http://www.africanpalliativecare.org/index.php?option=com\\_content&view=article&id=144&Itemid=79](http://www.africanpalliativecare.org/index.php?option=com_content&view=article&id=144&Itemid=79)

FHI 360. — 'Standard operating procedures: Palliative care for infants and children living with HIV.'

Washington, DC: FHI 360, 2009

[http://www.fhi.org/en/HIVAIDS/pub/guide/res\\_SOP\\_Pediatric\\_PalliativeCare.htm](http://www.fhi.org/en/HIVAIDS/pub/guide/res_SOP_Pediatric_PalliativeCare.htm)



Amery J, Editor, — 'Children's palliative care in Africa.'

London, United Kingdom: Oxford University Press, 2009

Doyle D, Hanks G, Cherny N, Calman K. — 'Oxford textbook of palliative medicine.' 3rd Edition.

London, United Kingdom: Oxford University Press, 2005

Bond C, Lavy V, Woolridge R. — 'Palliative Care Toolkit: Improving care from the roots up in resource-limited settings.'

World Palliative Care Association: London, United Kingdom, 2008

<http://www.helpthehospices.org.uk/our-services/international/what-we-do-internationally/education-and-training/palliative-care-toolkit/get/>



FHI 360. — 'Standard operating procedures: Palliative care for adults and adolescents living with HIV.'

Washington, DC: FHI 360, 2009

[http://www.fhi.org/en/HIVAIDS/pub/guide/res\\_SOP\\_Adults\\_PalliativeCare.htm](http://www.fhi.org/en/HIVAIDS/pub/guide/res_SOP_Adults_PalliativeCare.htm)



### Mental health integration guidelines and handbooks

WHO. — 'Integrating mental health into primary care: A global perspective.'

Geneva, Switzerland: WHO, 2008

[http://www.who.int/mental\\_health/policy/Integratingmhintoprimarycare2008\\_lastversion.pdf](http://www.who.int/mental_health/policy/Integratingmhintoprimarycare2008_lastversion.pdf)

WHO. — 'Organization and systems support for mental health interventions in anti-retroviral (ARV) therapy programs.'

Geneva, Switzerland: WHO, 2005

[http://whqlibdoc.who.int/publications/2005/9241593040\\_eng.pdf](http://whqlibdoc.who.int/publications/2005/9241593040_eng.pdf)



### Social and spiritual support guidelines and handbooks

Hospice and Palliative Care Association of South Africa and Open Society Institute. — 'Legal aspects of palliative care.' 2009

[www.osf.org.za/home](http://www.osf.org.za/home)

Southern Africa AIDS Trust (SAT). — 'Counselling guidelines on palliative care and bereavement.'

Johannesburg, South Africa: SAT, 2012

[http://www.satregional.org/publications/en/guidelines\\_counselling\\_palliative\\_care\\_and\\_bereavement](http://www.satregional.org/publications/en/guidelines_counselling_palliative_care_and_bereavement)



### PLHIV and family self-care tools

FHI 360 Viet Nam. — 'Living positive, living well: A self-care handbook for people living with HIV and their caregivers.'

FHI 360, 2010



FHI 360 Cambodia. — 'Self care series: Book two. Living with hope and staying healthy for people living with HIV.'

FHI 360, 2004



## Step 5: Monitor and revise implementation plan as needed

### KEY POINTS



- Periodically assess integration progress and service quality
- Update and revise integration plan as needed.

### Periodically assess integration progress and service quality

HIV services can track the effectiveness of integration by conducting routine quality assurance reviews. A short checklist that measures quality in relation to human resources, technical resources and monitoring and evaluation can be employed on a regular basis (eg. once every six months).

See 'Further reading' opposite, for examples of palliative care checklists.

In addition, HIV services should review palliative care service data on a monthly basis along with other HIV clinical data. This will provide important information about any areas that need more focus.

### Update and revise integration plan as needed

Inevitably, adjustments will need to be made to any or all of the elements of palliative care integration. After assessing for quality, the HIV service team can update the palliative care plan to accommodate areas that require improvement. For example, additional training or mentoring might be needed, or barriers to morphine prescription might need to be addressed.

## CD-ROM



African Palliative Care Association (APCA). — 'APCA standards for providing quality palliative care across Africa: A handbook of palliative care in Africa.' Kampala, Uganda: APCA, 2010

[http://www.hospicecare.com/standards/APCA\\_Standards\\_AW.pdf](http://www.hospicecare.com/standards/APCA_Standards_AW.pdf)

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FHI 360. — 'Palliative care checklist.'

Washington, DC: FHI 360, 2010

<http://www.fhi360.org/NR/rdonlyres/efpjbigozd6cdz64an3q7sz2ebdhoq3gudsqwvabrc2mg5jf26nczjplqa7ze3zqd3j24kh7lbk/PCChecklist.pdf>

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FHI 360. — 'Standards for improving the performance and quality of services in palliative care programs.'

Washington, DC: FHI 360, 2009

[http://www.fhi360.org/en/HIVAIDS/pub/res\\_PC\\_Standards\\_QualityServices.htm](http://www.fhi360.org/en/HIVAIDS/pub/res_PC_Standards_QualityServices.htm)

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## Section 5

# Examples of integrated palliative care in different care settings

### Integration into HIV/ART clinic settings

#### **Reach Out, Mbuya Parish HIV/AIDS Initiative, Uganda**

In Uganda, HIV outpatient doctors and nurses have been trained and certified in palliative care. At Reach Out's HIV outpatient clinic, for example, healthcare workers assess for pain and other symptoms, prescribe morphine for those who need it, and supervise follow-up care provided by home-based care teams. They store oral morphine and a small range of other palliative medicines in the clinic pharmacy. The clinic has a referral relationship with specialist palliative care through Hospice Africa Uganda.

#### **Public ART Clinic, DeAar, South Africa**

The public ART clinic in DeAar, South Africa works with Nightingale Hospice, a local NGO which provides palliative care. The hospice outreach team provides palliative care to patients at home and also offers respite care in a day centre. The hospice palliative care team routinely supports ART clinic clients and the ART clinic professionals are an integral part of the multidisciplinary palliative care team.

### Integration into hospital inpatient and outpatient care

All health professionals – attending physicians, nursing staff, social workers, chaplains and other professionals involved in patient care – should be able to provide and recognise the need for basic palliative care in their patients. In some hospitals, palliative care teams provide services to patients in wards, particularly post-operative wards, where pain management is often needed.

#### **Charlotte Maxeke Hospital, Johannesburg, South Africa**

The Hospital Palliative Care Team at Charlotte Maxeke Hospital in Johannesburg, South Africa, provides an advisory service that integrates palliative care with the curative management of patients in the hospital. It also

accepts referrals from other hospitals, health centres and the community. The team is available for all departments: surgical, medical, the HIV/AIDS clinic, gynaecology, obstetrics, orthopedics and pediatrics. They provide palliative care training to staff and medical students. The team is led by a doctor and palliative care-trained nurses, and links patients and their families to Soweto Hospice and other community-based care providers.

## Integration into primary health care

### **Primary health clinic, Mabvuku, Zimbabwe**

In Mabvuku, Zimbabwe, the local NGO-run hospice provides clinical and outreach palliative care on a scheduled basis from the primary health clinic. The community groups in the area work together with the clinic and the hospice to follow up with patients and their families to provide basic care, teach family members how to care, loan assistive devices such as wheelchairs and bedpans, and provide adherence and other forms of psychosocial support. The teamwork between the clinic staff, the hospice outreach team and the community members makes it possible to meet many of the patients' needs either directly or through referrals.

### **Kerala, India**

The State Government in Kerala, India, has mandated that those working at the primary care health level should be trained in palliative care, and primary health care facilities should link to tertiary and community-based palliative care services.

## Integration into community and home-based care

An important aspect of palliative care integration is training community home-based care (CHBC) teams to conduct basic symptom assessment and review patients' psychosocial and

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spiritual needs. In order for CHBC teams to offer quality care at the community level, they need to be supervised and mentored by more senior clinicians. They also need access to basic palliative care medicines.

### **Nepal**

Community home-based care teams across Nepal are led by a nurse and supervised by clinicians in local HIV care centres. PLHIV are trained and partnered with a nurse and both provide care to clients in tandem. There is a strong system of referrals to and from clinics and hospitals and community palliative care leading to high levels of retention in care, adherence and satisfaction with care.

### **Vietnam**

In Vietnam, community home-based care teams carry home-care kits, which include a range of analgesics such as paracetamol, ibuprofen and codeine. Kits are stocked by the local hospital where the team is based and team members are trained in their use. This enables the teams to provide a wider range of symptom management to PLHIV in the home under the supervision of HIV clinic staff.

### **Limpopo Province, South Africa**

At Good Hope Home Based Care (GHHBC) in Limpopo Province, South Africa, community caregivers were trained in palliative care as part of the Integration of Community Palliative Care Project (ICPC). The project provided training and resources to improve the organisation's capacity to offer palliative care (eg. bicycles for transport and caring equipment and kits). It also brought together the home-based care providers with the local clinic staff, who were also trained in palliative care.

Home-based care providers and clinic staff now work together to provide both clinical and home-based palliative care to patients and their families in the surrounding communities.

GHHBC also involved a pastor in the multidisciplinary team, which has led to improved access to spiritual and social support for clients and families. Through integrating palliative care and by working together, the clinic and the GHHBC are implementing a comprehensive service.

## Integration into closed settings

Palliative care is just as necessary within a closed setting, such as a drug rehabilitation centre or prison. When serious illness, especially at end of life, is experienced by an individual in a closed setting they are dependent on the limited resources available within that setting. Access to ART in closed settings is not always possible, so correctional healthcare workers need training in the management of palliative care in all phases of disease. Access to basic medicines to manage symptoms is also of critical importance.

Psychosocial support can often be provided by visitors who are part of the facility's human resources either through staff or volunteerism. Social workers may or may not be available within the setting, but their role needs to be taken up by the team members. Making contact with family outside of the closed setting is a very important aspect of providing palliative care when it is not possible for the patient to be released.

In parts of China and Vietnam, PLHIV are trained as peer educators to provide psychosocial support to peers.

In Indonesia, the prison/correctional system has worked hard to train and equip prison staff in HIV symptom management and psychosocial support in the face of extremely constrained resources.

In South Africa, the Hospice and Palliative Care Association of South Africa (HPCA) is providing palliative care training for clinical staff from the Department of Correctional Services. There are also national guidelines on palliative care for prisoners.

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AIDSTAR-One. — 'Case Study: Mental health care and support.' FHI Viet Nam. Washington, DC, AIDSTAR One/JSI, 2010

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Ammassari A, Murri A, Pezzotti P, Trotta MP, Ravasio L, De Longis P, Lo Caputo S, Narciso P, Pauluzzi S, Carosi G, Nappa S, Piano P, Izzo CM, Lichtner M, Rezza G, Monforte A, Ippolito G, d'Arminio MM, Wu AW, Antinori A. — 'Self-reported symptoms and medication side effects influence adherence to highly active retroviral therapy in persons with HIV infection.' *Journal of Acquired Immune Deficiency Syndrome* 2001; 28(5):445-449.

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# Appendix 1:

## Types of HIV palliative care integration

Types of integration	Examples of services
<p><b>Cooperation</b></p>	<p><b>HIV and palliative care service twinning or partnership</b>            (where an HIV and palliative care service have a referral relationship with each other). In Uganda, ART clinics partner with Hospice Africa Uganda to provide their patients with pain treatment and other palliative care services (<i>Green K, site visit, May 2008</i>).</p>
<p><b>Coordination</b></p>	<p>A system of <b>formal referrals between HIV and palliative care</b> services and intermural meetings: The South Africa Integrated Community-based Home Care Programme is an example of this (<i>Defilippi and Cameron 2007</i>)</p> <p><b>Palliative care consultative team:</b>            A specialist team based in a hospital or hospice provides palliative care to those under the care of a variety of services. It includes inpatient, outpatient and home-based care consults</p> <p>This model is applied in the US by Montifore Hospital (<i>Selwyn et al 2003</i>).</p>
<p><b>Co-location</b></p>	<p><b>HIV and palliative care service offered by separate providers but in the same location</b>            An example of this is the inpatient palliative care unit added to a hospital in Grahamstown, South Africa, also offering HIV outpatient care (<i>Jameson 2007</i>).</p>



Types of integration	Examples of services
<p><b>Amalgamation</b></p>	<p><b>Where HIV and palliative care services are offered by the same providers and service</b></p> <p><b>Integrating palliative care into home-based care services:</b> This involves training, equipping and supervising traditional home-based care services to offer pain and other symptom assessment and management, skilled emotional support, bereavement care and spiritual care (<i>Downing et al 2010</i>)</p> <p><b>HIV outpatient clinics offering palliative care as part of routine HIV care and treatment</b> In Uganda, HIV services such as Reach-Out Mbuya Parish include nurses certified in palliative care and opioid prescription working in the outpatient clinic and supervising home-based care. They store oral morphine and a range of other palliative medicines. The Parish has a referral relationship with specialty palliative care through Hospice Africa Uganda (<i>Green K, site visit, May 2008</i>).</p>
<p><b>Assimilation</b></p>	<p><b>Full incorporation of palliative care for HIV, cancer and other disease in the public health care system</b> One of few places in resource poor contexts where this has occurred is the state of Kerala, India, where the state government has officially incorporated palliative care into all levels of the healthcare system, including provision for provider training, standards and medicines. These generalist palliative care services are linked to specialty palliative care providers who provide training, quality assurance support and care for complex cases (<i>Paleri 2010</i>).</p>

Source: Green K. (2012c)

## Appendix 2: Palliative care steps by service type

Activity	Outpatient	Inpatient	Primary Care	Community and home-based care
Develop an interdisciplinary team	<input type="radio"/>		<input type="radio"/>	<input type="radio"/>
Train service providers in adult and pediatric palliative care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Include standardised pain and other symptoms assessment tools as part of routine patient intake and follow-up forms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ensure identified symptoms are managed for optimal reduction of patient suffering	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Include a psychosocial assessment (including screening for alcohol and drug use) as part of patient intake and follow-up forms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use client-held record forms where the palliative and other care plans are documented and updated as needs change; keep a copy in patient file	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ensure providers regularly assess pain and other symptoms in all patients. Develop service provider skills in appropriate classification of pain (eg. nociceptive and neuropathic)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establish a referral network and systems with services that provide psychosocial support, spiritual care, legal services and assistance to children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Develop supportive counseling services for clients, families, and caregivers, including bereavement counseling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Where possible, provide assistive devices to support home care (eg. wheelchairs and bedpans).	<input type="radio"/>			<input type="radio"/>

Activity	Outpatient	Inpatient	Primary Care	Community and home-based care
Identify volunteers (often PLHIV or community members) who work in the inpatient facility and can provide on-going support		○		
Develop skills in end-of-life care		○		○
Provide clear, effective discharge plans and necessary instructions, medicines, and information for patient and caregivers		○		
Make provisions for last rites, funerals and burial		○		○
Work closely with CHBC services to ensure close linkages for referral and, if feasible, supervision and mentoring of CHBC service providers	○		○	
Help stock and restock medicines and supplies in home-care kits	○		○	
Reinforce palliative care provision through re-orienting the thinking of CHBC teams and providing routine supportive supervision and mentoring				○
Equip CHBC teams with appropriate palliative care medicines				○
Introduce danger sign algorithms so CHBC teams are better able to refer clients responsively and effectively				○
Create formal service partnerships with primary care sites, HIV out- and inpatient care to promote client access to care.				○

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## Appendix 3:

# Guide to palliative care screening and assessment tools

Service leaders may find the following tools useful. Please note that some are also available on the CD-ROM.

### **Hospital Anxiety Depression Scale (HADS)**

The Hospital Anxiety and Depression Scale (HADS) is a valid and reliable self-rating scale that measures anxiety and depression in both hospital and community settings.

Find out more:

<http://www.gl-assessment.co.uk/products/hospital-anxiety-and-depression-scale-o?gclid=CP-2vJrVrLACFYt-fAodLxHRUw>.

### **Memorial Symptom Assessment Scale – Short Form**

The Memorial Symptom Assessment Scale – Short Form delineates the intensity, frequency, and level of distress of 32 physical and psychological symptoms.

See Appendix 4 for a sample copy of the form.

### **MOS-HIV Health Survey**

The MOS-HIV Health Survey evaluates patient outcomes in clinical trials and other studies of people with HIV/AIDS.

Find out more:

<http://www.mapitrust.org/services/questionnairelicensing/cataloguequestionnaires/116-mos-hiv>.



### **Palliative Outcome Scale**

The Palliative Care Outcome Scale (POS) is a tool to measure patients' physical symptoms, psychological, emotional and spiritual needs, and provision of information and support at the end of life.

The POS was developed by Professor Irene Higginson at King's College London. It is a validated instrument that can be used in clinical care, audit, research and training. It is widely used internationally, including in Europe, Australia, Asia, Africa and America. References for validation, including for linguistic validation, can be found here: <http://pos-pal.org/index.php>.

Before you use the POS, please register here: <http://pos-pal.org/index.php>.



### **African Palliative Care Association's (APCA) African Palliative Outcome Scale**

The development of the APCA African POS was led by the African Palliative Care Association (APCA). It has been validated across diseases, countries, settings and languages.

Before you use the APCA African POS, please register here: <http://pos-pal.org/index.php>.

### **Paediatric Palliative Outcome Scale (Africa)**

A Paediatric Palliative Outcome Scale for Africa is currently being validated and will be available for use by the end of 2012. The project has been led by the African Palliative Care Association in collaboration with the International Children's Palliative Care Network (ICPCN).

# Appendix 4: Memorial Symptom Assessment Scale (Short Form)

Patient's Name \_\_\_\_\_ Date \_\_\_/\_\_\_/\_\_\_ ID# \_\_\_\_\_

## MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Please note that this is a sample form only. Permission must be sought to reproduce.

Patient's Name \_\_\_\_\_ Date \_\_\_/\_\_\_/\_\_\_ ID # \_\_\_\_\_

**MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]**

**I. INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom DURING THE PAST WEEK, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→ → <b>IF YES:</b> How much did it <b>DISTRESS</b> or <b>BOTHER</b> you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
“I don’t look like myself”						
<b>If you had <u>any other symptoms</u> during the PAST WEEK, please list them below, and indicate how much the symptom <b>DISTRESSED</b> or <b>BOTHERED</b> you.</b>						
1.						
2.						

**II.** Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <u>all</u> the symptoms you have had during the PAST WEEK	→ → <b>IF YES,</b> How <b>OFTEN</b> did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Chang, V. T., Hwang, S. S., Feuerman, M., Kasimis, B. S. and Thaler, H. T. (2000), *The Memorial Symptom Assessment Scale Short Form (MSAS-SF)*. *Cancer*, 89: 1162– 1171. © 2000 Wiley. Used with permission.

## Appendix 5:

# Illustrative list of basic palliative care medicines

Drug name	Class	Clinical uses	Alternative drugs
Paracetamol	Non-opioid analgesic	Pain control Fever	
Aspirin	Non-opioid analgesic	Pain control Fever Sore mouth	
Ibuprofen	NSAID (Non-opioid analgesic)	Pain control Inflammation Fever	Diclofenac Naproxen Indomethacin
Codeine	Weak opioid analgesic	Fever Diarrhoea Cough	Dihydrocodeine
Morphine	Strong opioid analgesic	Pain control Breathlessness, cough Severe diarrhoea	Tramadol Oxycodone
Dexamethasone	Corticosteroid Adjuvant analgesic	Painful swelling and fever inflammation Poor appetite Drug reactions	Prednisolone
Amitriptyline	Tricyclic antidepressant Adjuvant analgesic	Nerve pain Depression	Imipramine Lofepamine
Diazepam	Benzodiazepine Adjuvant analgesic	Muscle spasm Anxiety and sleep Shortness of breath Seizure treatment	Lorazepam
Metoclopramide	Antiemetic	Vomiting Poor appetite	Domperidone
Haloperidol	Antiemetic Antipsychotic	Vomiting Hiccups Confusion and agitation	Chlorpromazine



Drug name	Class	Clinical uses	Alternative drugs
Magnesium trisilicate	Antacid	Indigestion Gastro-oesophageal reflux	Aluminium hydroxide Magnesium hydroxide
Loperamide	Antidiarrhoeal	Diarrhoea	Codeine Lomotil
Senna	Laxative	Constipation	Bisacodyl Magnesium hydroxide
ORS	Oral rehydration salts	Diarrhoea Rehydration	Ricewater Coconut milk
Chlorpheniramine	Antihistamine	Itch Drug reactions	Promethazine Hydroxyzine
Skin preparations			
Vaseline	Skin moisturizer and protector	Dry skin Skin protection	Aqueous cream
Gentian violet paint		Bacterial, fungal and viral skin infections	
Benzyl benzoate lotion	Scabicide	Scabies	Permethrin cream/ lotion
Clotrimazole 1% cream	Topical antifungal	Fungal skin infections	Whitfields ointment Minconazole cream
Chlorhexidine 0.05%	Antiseptic	Bacterial skin infection	Gentian violet

Source: Palliative care toolkit - Improving care from the roots up in resource-limited settings, published by Help the Hospices in association with the Worldwide Palliative Care Alliance. Reproduced with kind permission.

# CD-ROM Contents

## What's on the CD-ROM?

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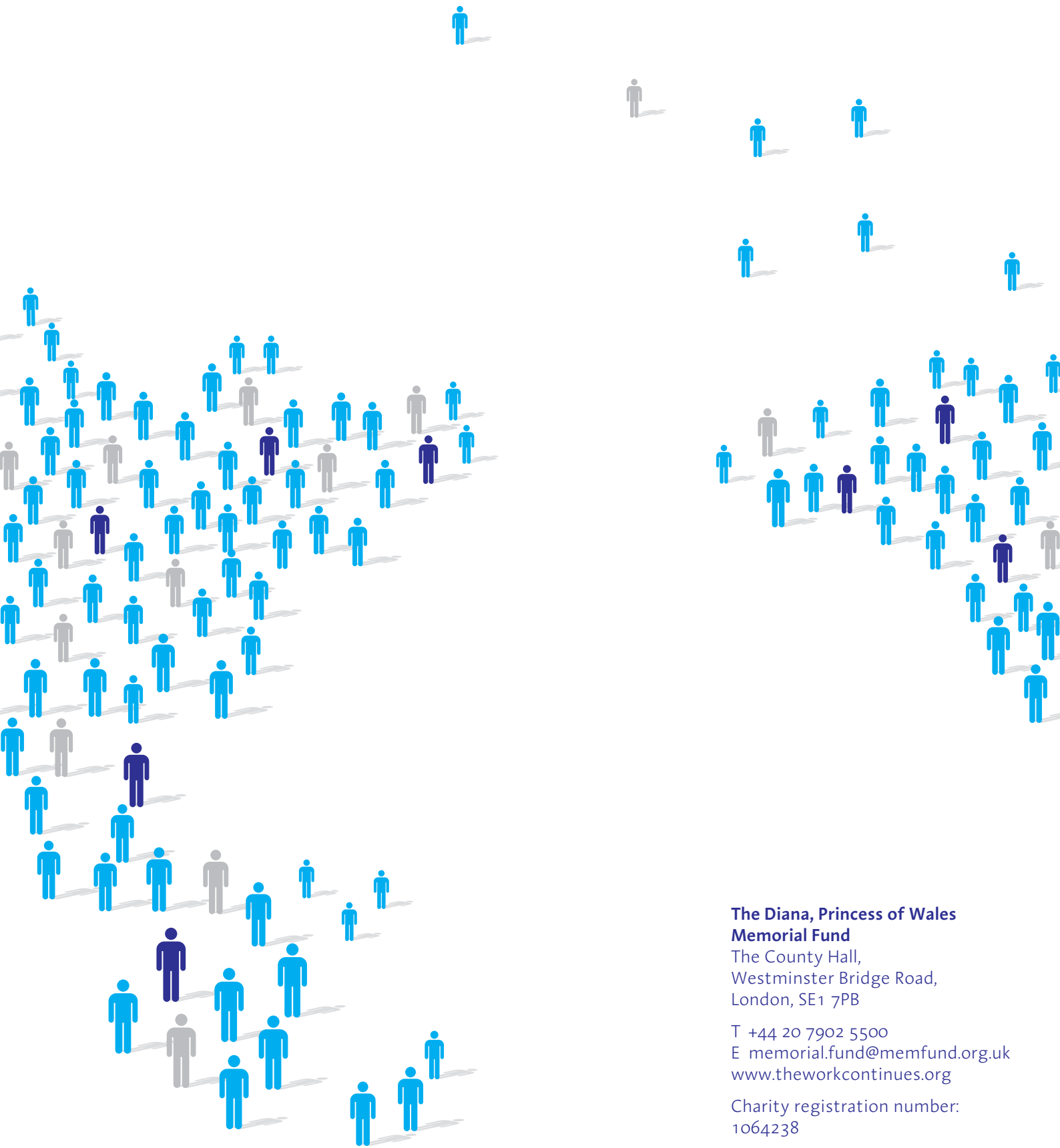
### Folder

- 01 General information
  - 02 Needs assessment and team building/tools
  - 03 Training curriculum and tools
  - 04 Access to essential medicines and opioids
  - 05 Clinical guidance, tools and SOPs
  - 06 Emotional and socioeconomic support tools
  - 07 Patient self-care guides and tools
  - 08 Quality assurance and standards
- 

*FHI 360 and The Diana, Princess of Wales Memorial Fund would like to thank the following individuals and organisations for kindly allowing their materials to be included on this CD-ROM:*

- *Abt Associates – [www.abtassociates.com](http://www.abtassociates.com)*
- *African Palliative Care Association (APCA) – [www.apca.org.ug](http://www.apca.org.ug)*
- *AIDSTAR – [www.aidstar-one.com](http://www.aidstar-one.com)*
- *Bryan Pearson for Africa Health – [www.africa-health.com](http://www.africa-health.com)*
- *Professor Irene Higginson, King's College London*
- *Help the Hospices – [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)*
- *Hospice Palliative Care Association of South Africa – [www.hospicepalliativecaresa.co.za](http://www.hospicepalliativecaresa.co.za)*
- *Southern African AIDS Trust – [www.satregional.org](http://www.satregional.org)*
- *World Health Organization (WHO) – [www.who.org](http://www.who.org)*





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