

# Integrated Community-based Home Care (ICHC) in South Africa

A review of the model implemented by the  
Hospice Association of South Africa



NATIONAL DEPARTMENT OF HEALTH  
GOVERNMENT OF SOUTH AFRICA

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Compiled by

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Contributors and thanks

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*Cover Photograph: Rural community, Empangeni, KwaZulu-Natal*

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## INTRODUCTION

*Caring for people with HIV/AIDS presents unique challenges. The progression of the disease is often unpredictable, making it necessary for any care programme to offer good symptom control and the best possible opportunities for rehabilitation. Given that most of our patients do not have access to anti-retroviral therapies, nutritional support, social and spiritual support and counselling all play an important role in a holistic care service.*

*(Letter from Sue Cameron, Pretoria Sungardens Hospice, and Joan Maston, Naledi Hospice)*

In the past few years, hospitals have become overcrowded and in many facilities AIDS patients outnumber patients with other illnesses. Doctors in at least two major hospitals in Durban say that between 55% and 65% of medical in-patients are HIV positive – the vast majority with AIDS-related illnesses. Medical beds at two hospitals in Pietermaritzburg and several rural hospitals are running at 120% over capacity because of AIDS (Bateman, 2001).

The influx of patients can influence the quality of care provided. For example, according to a report by the Free State Department of Health (2001), an average patient's stay in hospital ranges from four to eight days. AIDS patients who are in the late phases of the disease usually lose weight to the point where they cannot care for themselves and require longer term care – extending through to ongoing care. The Department of Health states that if the status quo is maintained, and patients continue to be treated in hospitals, then within the next three years, the number of beds will be exceeded by the number of patients hospitalised. The need for beds will continue to increase and there will be no place to care for patients with non-HIV related conditions.

Continuing with this example, the Free State Department of Health estimates that 90% of HIV/AIDS patients can be treated within a good home-based care environment, supported by step-down facilities that serve as a transition for patients between hospital and home care. According to this report however, home-based care services are poorly developed in the Free State. Only nine out of 80 towns have comprehensive home-based care services and 50 out of the 80 towns have selective home-based care for cancer patients. To date, primary health care staff is not sufficiently skilled to manage ill HIV/AIDS patients.

Home-based care is considered as an alternative to traditional institutionalised care, and focuses on palliative care within the home. Though expenses differ between hospitals, in KwaZulu-Natal the cost to the institution of caring for an inpatient is around R650 per patient per day. The increasing number of patients hospitalised for an extended period of time has stretched the resources of the health care system. Discharging patients into the care of a home care programme allows for a shorter stay at the hospital, making more beds available for other patients and reducing costs to the institution. Murchison Hospital in Port Shepstone reports that the average time spent in hospital has decreased from at least 14 days to 3.5 days for patients who are referred to a home-based care programme.

Hospital nurses are generally restricted in dealing with terminal patients because of their limited knowledge of palliative care, and also because hospital policy seeks to maximise patient turnover. Releasing patients into the care of competent agencies that deliver quality home-based care services can allow hospital staff to have peace of mind and enhance the morale of health care providers in the face of an overwhelming situation.

The care and support needs of HIV positive people, people with AIDS and their families have been well documented. For example, one research study conducted in a South African township identified various themes in relation to the needs of people living with HIV/AIDS, including poverty and isolation; hunger; fear for the future of their children; difficulty accessing welfare grants; lack of male participation in HIV/AIDS services; difficulty with disclosure and acceptance; unsympathetic health and social service workers.<sup>1</sup> These needs can be addressed on a continual basis through a home-based care programme.

### The purpose of this report

In 1999 POLICY Project supported seven hospices to incorporate the Integrated Community-based Home Care (ICHC) model into their operational activities. In the light of the grant period drawing to an end, this report was commissioned to document the critical elements of the ICHC model and reflect on the experiences of those working in the field. Objectives of the research were to:

- ❑ identify and discuss key similarities and differences between the hospice ICHC model and other home-based care models used in South Africa;
- ❑ identify and critically review the core elements related to the ICHC model as implemented by Hospice Association of South Africa;
- ❑ highlight key aspects of best practice related to the hospice ICHC model.

### Methodology

This report outlines information from a literature review and field research pertaining to these three objectives. Differences and similarities of the various models of home and community-based care are illustrated in the following section. Core elements of the ICHC model are identified in six themes. Finally, aspects of best practice are illustrated in the key issues section.

Field research for this report was conducted at seven sites during April and May 2002.

The following sites were visited:<sup>2</sup>

- ❑ Helderberg Hospice, Somerset West, Western Cape
- ❑ Naledi Hospice, Bloemfontein, Free State
- ❑ Pretoria Sungardens Hospice, Pretoria, Gauteng
- ❑ Zululand Hospice Association, Empangeni, KwaZulu-Natal
- ❑ South Coast Hospice, Port Shepstone, KwaZulu-Natal
- ❑ St Bernard's Hospice, East London, Eastern Cape
- ❑ St Francis Hospice, Port Elizabeth, Eastern Cape

The format of the visits included interviews with the hospice's professional nurse supervisors, community caregivers, hospice administration and home visits to patients. In addition to the site visits, Dr Liz Gwyther of the Hospice Association of South Africa (HASA) was interviewed.

A literature review was conducted on home-based care. A video created by HASA on the ICHC model entitled *An Introduction to the Integrated Community-based Home Care Model (ICHC)* (2001) was also reviewed. Information on national guidelines on home-based care was obtained from the HIV/AIDS Directorate of the National Department of Health.

1 Russell & Schneider (2000)

2 A list of interviewees and an interview schedule are listed in Appendix 1.

There are few published resources on the ICHC model of home-based care, therefore, unless indicated, the information in this report was obtained through interviews with ICHC staff or visits to patients in the community with caregivers.

### Models of home-based care

The impact of HIV/AIDS on the health care system has increased the need for treatment and altered the type of care needed for hospitalised patients. The progression of HIV to AIDS varies, ranging from a few months – usually in the case of babies – through to more than a decade. The advanced stages of HIV are chronic, with patients experiencing periods of relative health between relapses, or succumbing to various opportunistic infections.

Home-based care provides an alternative to institutionalised health care, and has received greater emphasis with the advent of HIV/AIDS. The World Health Organisation (2001) defines home care as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximal level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventative, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories.

According to the South African Guidelines on home-based care and community-based care,<sup>3</sup> this type of de-institutionalised care addresses several problems, including:

- ❑ shortage of hospital beds;
- ❑ inadequate number of medical, nursing and allied health professionals in the public sector;
- ❑ lack of resources for treatment and drugs;
- ❑ hospital over-crowding combined with staff shortages, which make it difficult to manage patients with terminal illnesses;
- ❑ high costs of institutional care.

In order to provide appropriate care and support for people with HIV/AIDS, especially in less developed countries with minimal resources and health budgets, a comprehensive integrated approach that addresses the medical, psychosocial, spiritual and emotional needs, is necessary. Community-based care, specifically in relation to HIV, includes any aspect of care along a continuum of illness, from the time a person is infected through to terminal illness. Care may continue in the form of counselling after the patient's death for those who are left behind. Community care is usually based outside formal health facilities, but is built on partnerships with formal government sectors, such as health, welfare and development sectors.<sup>4</sup> Home-based care is an aspect of community-based care that focuses primarily on physical/medical and palliative care of the patient at home, with the support of family and the immediate community. The focus on the physical care of the patient means strong links with the formal health sector.

Both community and home-based care are essential in providing comprehensive and continual care for patients and their families within their communities. Five models of care have been suggested by the Department of Health. They are the:

1. community-driven model;
2. formal government sector model;
3. integrated home/community-based care centre model;

<sup>3</sup> Department of Health (2001)

<sup>4</sup> Russell & Schneider (2000)

<sup>5</sup> Department of Health (2001)

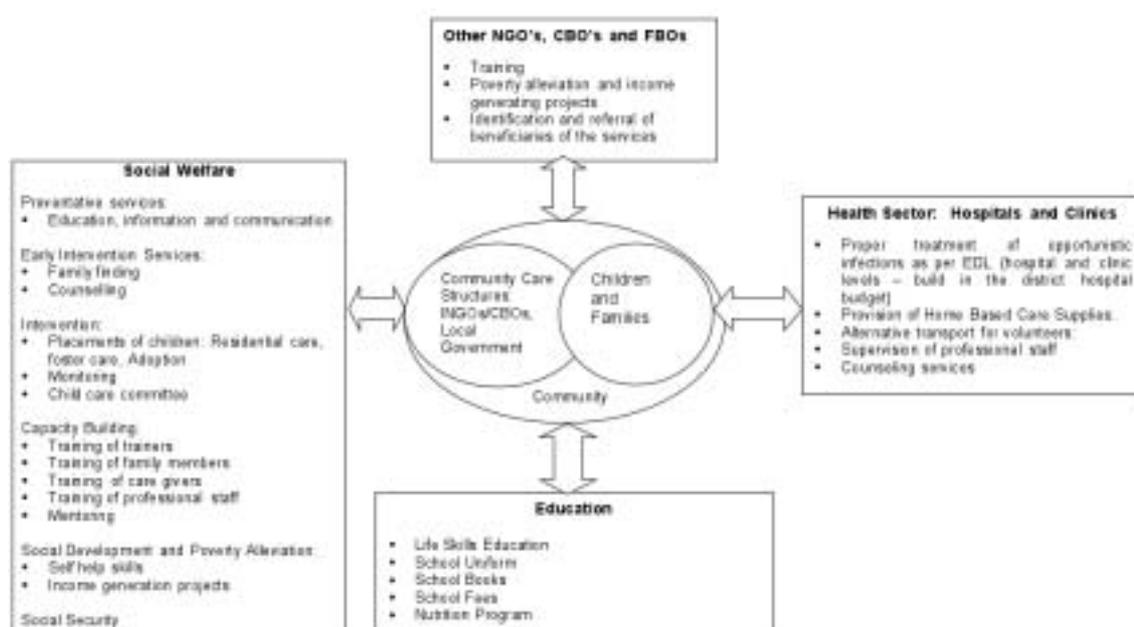
4. NGO home/community based care model;
5. hospice integrated community home-based care model (ICHC).<sup>5</sup>

These models purport to incorporate all levels of society – the formal health sector, relevant NGOs/community-based organisations (CBOs), faith-based organisations (FBOs) and the community – and have the common goal of providing adequate care to patients and their families within the context of the community, taking into consideration socioeconomic conditions, needs and constraints. Each model has a coordinating body and has its own niche in the provision of health care, depending on the coordinating body. Each model is contextually situated, as are the factors involved in providing community/home-based care in the area, such as the availability and capability of structures or organisations already present in the community.

The success and sustainability of any model is dependent upon, amongst other things, the availability of resources, the level of community participation and the level of ongoing commitment and organisational capacity of the coordinating body. Whilst community participation is highly dependent on a number of factors that often cannot be controlled by programme implementers, resources and organisations can be identified and developed. If the coordinating body is already well-established in the community, there is an added degree of certainty about the capacity and sustainability of programmes it implements.

### 1. Community-driven model

The community-driven model<sup>6</sup> is based on integrated service provision through locally-driven initiatives. In all other models, there is a central structure or coordinating organisation. However, whilst this model could be attached to a community structure, this is not necessary. A Community Developer is responsible for liaising with partner organisations and training volunteer caregivers, who then deal directly with patients and their families. Additionally, approaching government departments or NGOs may be approached for resources.

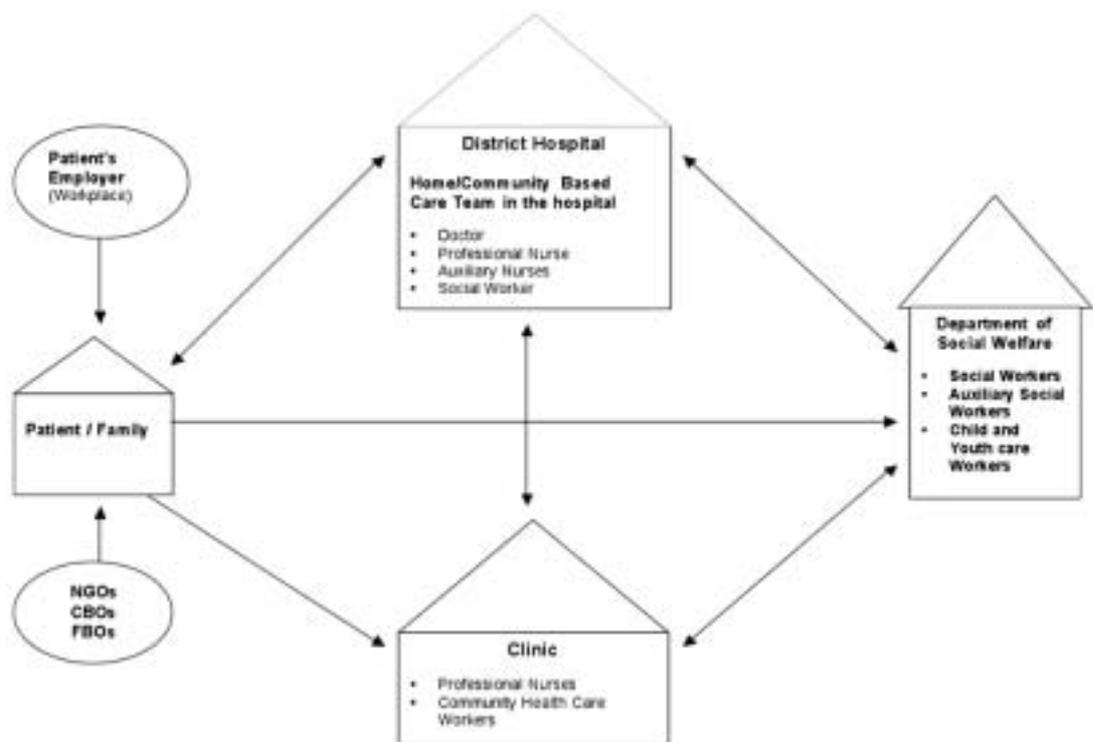


<sup>6</sup> Information and graphic representations of home-based care models were obtained from the Department of Health's *National Guideline on Home-based Care and Community-based Care* (2001).

## 2. Formal government sector model

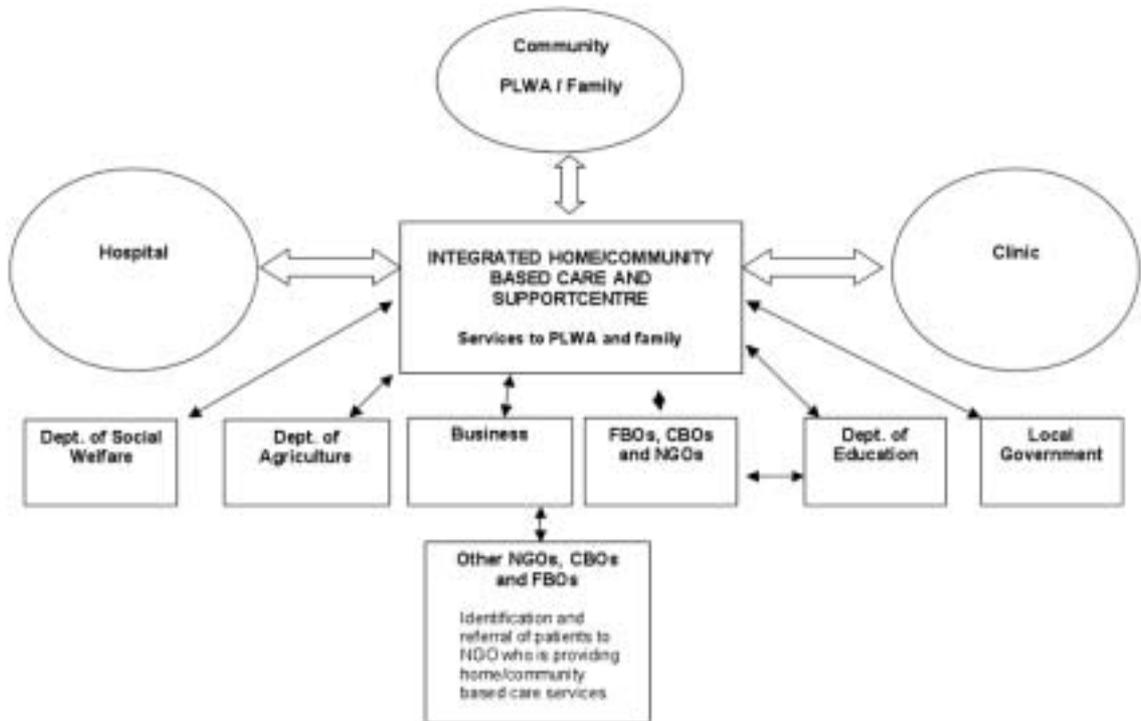
Led by government departments such as health and welfare, the formal government sector model works in collaboration with various sectoral partners. The home/community-based care programme is coordinated at the district level by a multidisciplinary team of doctors, nurses and a social worker within the hospital structure. A patient is treated at the hospital and where possible, transported home by the hospital. Home visits are conducted by a professional nurse and community health care workers. The patient can go to the clinic for follow-up treatment and be referred back to the hospital if necessary. Other community organisations may assist the family and patient where needed.

The advantage of this model is that the formal health and welfare services that coordinate the programme are already well established and receive financial and policy support from government.



## 3. Integrated home/community-based care centre model

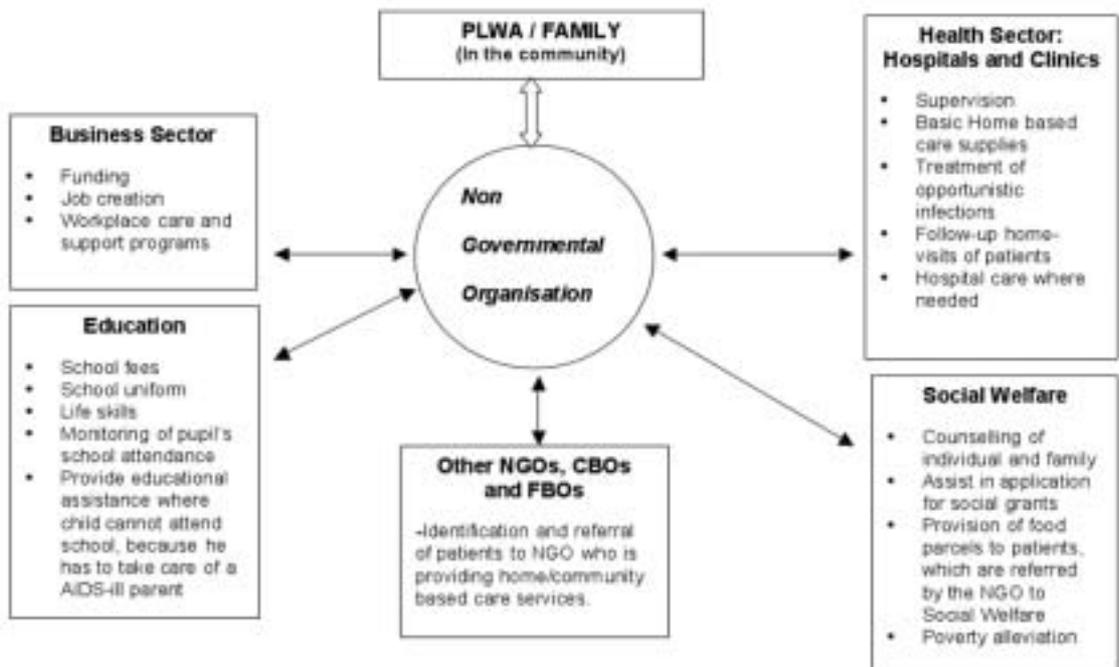
This model is structured around a care centre, which is located within the community, possibly attached to a church or school, and coordinates home-based care services. The centre is volunteer-run – however the Departments of Health and Welfare may send a professional nurse or social worker to offer services at the centre. The centre should offer various services, including pre- and post-test counselling; HIV testing; training of family members and community caregivers as volunteers; distribution of IEC materials; facilitation of income generating projects; supervision and monitoring of community caregivers; conducting of home visits and patient follow-ups; and referral to and from hospital and other service providers. The centre could also act as a halfway house and provide day care for patients.



**4. NGO home/community-based care model**

The NGO home/community-based care family model is similar to the previous model in that it is located within the community itself. The entire home-based care programme is initiated by a coordinating NGO. Needs are identified and services are provided by the NGO – however, the home care programme can be financially supported by the business and health sectors, social welfare organisations, other NGOs, CBOs and FBOs. The home-based care team may include a professional nurse, social worker, project coordinator and volunteers or community caregivers who are based at the NGO.

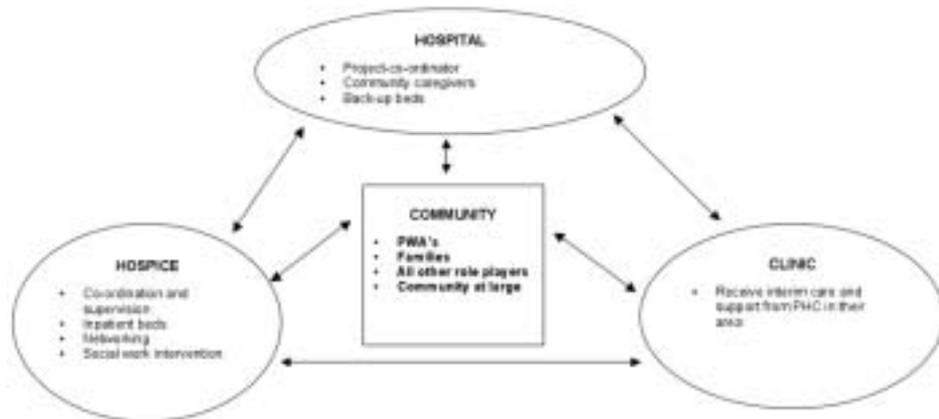
If the central NGO is well established and is self-maintaining, it can act as an effective coordinator.



### 5. Integrated community and home-based care (ICHC) model

As will be illustrated in more detail in the following sections of this document, this model is supported by a hospice. The ICHC model emphasises a continuum of care between all sectors of the health care system, and emphasises palliative care.

ICHC is similar to the NGO model but has the additional benefit of being managed by an NGO that is already well-established and self-supporting. This is beneficial as it cuts down on the time needed to set up coordinating structures enabling the rapid development of a home care network.



## The ICHC model in practice

### Hospice care in South Africa

*Hospice is not a place or an institution but a philosophy of care in which the person is considered of primary importance and the disease is secondary (Buckingham, 1983).*

The backbone of the ICHC model is hospice. Hospice is an international NGO that was initially developed in the United Kingdom to provide care for terminally ill patients in their homes or in hospitals or within in-patient wards run by the organisation. At the core of hospice's work is palliative care, which is defined by the World Health Organisation as the active, total care of a patient whose disease is not responsive to curative treatment.

Palliative care focuses on quality of life rather than on cure or recovery. It is person-oriented and not disease-oriented. According to the International Association for Hospice and Palliative Care, the message of palliative care is that whatever the disease, however advanced it is and whatever treatments have already been given, there is always something that can be done to improve the quality of the life remaining to the patient. Hospice deals holistically with the symptoms of terminal illness, including psychological problems, pain and symptom management. Hospice and palliative care originated because of the belief that terminally ill patients were not receiving optimal care and there was distrust between the practitioners of palliative care and orthodox medicine.

Traditional palliative care models that were originally designed to deal with terminal cancer patients are no longer adequate to meet the complex needs that are resultant of the HIV/AIDS pandemic (Sanei, 1998). However, the essential elements of palliative care are still crucial in providing comprehensive care and support for People Living with HIV/AIDS (PLWHA).

In South Africa, according to the national Standards of Palliative Care (Uys & Marston, 2000), core elements of hospice's palliative care include: access to care from health care workers skilled and knowledgeable in palliative care; collaborative care; client and family as the unit of care incorporating community resources; pain and symptom management using specific guidelines of holistic care; family support into the bereavement period; and volunteer support.

Traditionally hospice treated older cancer patients whose care was financed by medical aid schemes. Currently, a large number of terminally ill patients are young and suffer from AIDS-related conditions and typically do not have access to private medical services or support. In reaction to the changing dynamics and demands for palliative care, South Coast Hospice developed the ICHC model. This was adopted by the Hospice Association of South Africa (HASA).<sup>7</sup>

### Understanding the ICHC model

In 1997, the South Coast Hospice was the first hospice to implement the ICHC model by the Department of Health, through the USAID-funded POLICY Project, as an extension of the hospice's experience in palliative care and outreach activities. Two

<sup>7</sup> Founded in 1987, HASA is today a network of 52 member hospices countrywide that work to facilitate the development of programmes to provide people living with terminal illness the opportunity to live and die with dignity.

years later the Department of Health provided funding to HASA to manage the implementation of the ICHC model into the operational activities of seven hospices around the country. Pilot projects were established in Bloemfontein, Port Elizabeth, East London, Empangeni, Pretoria, Port Shepstone and Somerset West (see Appendix 3 for more details). These pilot sites include rural and metropolitan settings, and sites that had existing home-based care activities. Hospices at the pilot sites have continued with their established hospice programmes, with the addition of the ICHC home-based care component.

The ICHC model sets out to provide the best quality of life for patients and their families.<sup>8</sup> As can be seen in the model, the core of the programme is the person with a terminal illness and that person’s family, as such, reflects a patient-centred approach. This core is then supported by the micro-community, including neighbours, extended family, and various agencies including the formal health care sector, community-based organisations and hospice, that are also focused on caring for the patient and family. This represents a continuum of care and support for patients.



### Main characteristics of the ICHC model

Characteristics of this model include: a shift from relying on the care of professional nurses to community-based caregivers, and from institutionalised settings to home care; a focus on both the patient and the family; and emphasis on education with the aim of decreasing the transmission of HIV by empowering families and the community with knowledge and skills.

The model can be implemented in rural, semi-urban and metropolitan settings, and services are provided on a free or on a pro rata basis, depending on the financial situation of the patient.

Hospice provides the overall management of the home-based care programme as well as various forms of support through the existing hospice structure to assist the programme.

The ultimate responsibility for the provision of quality nursing care rests with professional nurse supervisors from the hospice. The work of the caregivers in the community is supervised by at least one trained nurse. Communication between the caregivers and supervising nurses is critical to ensure quality of care.

<sup>8</sup> Basic information on the ICHC model is referenced from a video entitled, *An Introduction to the Integrated Community-based Home Care Model (ICHC)* (2001) by the Hospice Association of South Africa.

*The supervising nurse from St Francis Hospice drops caregivers off in their areas. They then phone her to report on patients who require urgent feedback, and to update her on whom they had seen and the patients' needs. This system of communication makes their work more efficient. Check-ups, follow-up on hospital visits, and the distribution of medication and food parcels are also handled in this manner.*



*A nurse and caregiver from St Francis Hospice, Port Elizabeth, taking a break at a patient's home.*

The support of doctors in offering advice and prescribing medication to the home-based care programme varies. Some hospices have in-house doctors, while others have doctors who volunteer at hospices on a part-time basis. Some hospices do not have the services of a doctor and refer patients in need of advanced care to the hospital.

*The supervising nurse for the home-based care programme at Helderberg Hospice meets every morning with the rest of the hospice staff, along with a doctor who volunteers part time. They discuss their patients' health, share experiences and difficulties, and ask the doctor for suggestions on treatment.*

Originally, hospice's in-patient facilities were limited to hospice patients. However, these beds can be extended to home-based care patients who are in need of pain management or whose families need respite from caring for the patient.

*One problem experienced at St Francis Hospice was that when a patient was ready to be released from in-patient care, the patient's family was not always willing to take the patient back home again.*

Some hospices have an in-house social worker who assists patients and their families with various issues, including the placement of children and accessing financial assistance. In cases where there is no social worker, the caregiver provides this service.

The recruitment and training of caregivers is provided by hospice. The course includes basic nursing, hygiene, general and bereavement counselling skills, general and clinical aspects of HIV/AIDS and palliative care.

## Themes of the Integrated Community-based Home Care model

There are several basic themes of the ICHC model:<sup>9</sup>

1. Community orientation of caregivers
2. Quality care in the home
3. Relationship with health services
4. Support networks in the community
5. Continuum of care
6. Bridging education and prevention

### 1. Community orientation of caregivers

Caregivers are an integral part of the ICHC model. Their relationship with the community is vital to the success of the home-based care programme, so hospice takes great care in selecting them. Criteria commonly used for selection include: residence in community; current unemployment; previous volunteer work; ability to demonstrate empathy with patients; ability to cope in stressful situations; commitment to community; and good communication skills. Previous training in counselling and appropriate levels of literacy are also seen as preferable.



*Caregivers and a driver at Naledi Hospice, Bloemfontein.*

Caregivers are generally paid members of the hospice staff and are typically contracted for a one year period. While salaries differ between hospices, they are generally very low and do not include additional benefits. For example, at one hospice, there are ten caregivers who are paid R1 200 initially. After three months their salaries increase to R1 500 and a 10% annual increment is applied. Alternatively, another hospice's caregivers receive R1 750 per month with an additional R250 travel allowance. They are required to transport themselves to their patients, which can cost up to R30 per day. Those hospices linked to Provincial Administration support of caregivers pay the Department of Health reimbursement of R620 per month.

<sup>9</sup> The remainder of the report is based on information from interviews with hospice administration, caregivers and professional nurses during visits to ICHC pilot sites.

The educational standard for caregivers is generally low and has been seen by some as a limitation in the training process.

*In Enseleni, KwaZulu-Natal, the average education in the primary area of operation is grade three and many caregivers who underwent training with Zululand Hospice Association could not read and write, and could only speak Zulu. Staff at the hospice suggested that 'lots of commonsense and perseverance' was required during training.*

### Training

Caregivers attend a three month course on basic skills of home care and palliative care. Training is holistic and based on the Department of Health's curriculum for home-based care, developed by HASA, which includes modules on the role of caregivers; basic information on STDs, HIV/AIDS and TB; teaching and communication skills; spiritual and cultural issues; infection control; social support; principles of palliative care principles and basic nursing care; nutrition; and care of the caregiver. There is an initial 70 hours of classroom input linked to 160 hours of clinical placement, shared between hospice, primary health care clinics and participating hospitals.



*Caregiver training at Zululand Hospice Association*

Training for caregivers continues intermittently after the initial skills are given. There is a review of quality of care provided by caregivers every six months and the findings on areas of improvement are scheduled into the training programme, as is education on emerging health care issues, such as cholera. Caregivers can also suggest specific topics into the training.

Because of the low pay, hospices risk training caregivers and then losing them to better paid jobs elsewhere in the health care sector.

### Activities

The official work hours for caregivers vary between six and eight hours a day, depending on the programme. However, most caregivers are generous with their

time and are willing to spend as much time as is needed with patients or patients' families who need them. For example, if a patient becomes seriously ill or dies, caregivers are known to work through the night assisting the family by contacting the police and other logistical arrangements, as well as counselling the family.

One challenge of home-based care programmes is the isolation of patients who are cared for at home. Day care programmes may be offered as part of home-based care, generally once a week for those patients who are not home-bound. Day care provides patients with a break from their everyday lives, offers social opportunities with people in similar circumstances, a break from boredom, a hot meal and recreational activities.

*St Bernard's Hospice, East London, runs a day clinic as part of its home-based care programme once a week. All patients that are 'on the books' and are well enough to get there can attend. Patients in a community meet at a certain time at a pick-up point and are transported to the day care. Breakfast and lunch are served, patients are checked by the doctor and receive medication if required, and they spend time socialising and hearing other people's experiences of being HIV positive. It is apparent from the caregivers that this is a very special time. People seem to be positive and support each other during these day visits.*

*As part of day care at Sungardens Hospice, Pretoria, various representatives of social services in the community are invited to speak, including social workers who inform patients about forms of support that are available. There is a short exercise programme, the patients sing and make music, and often ministers from the community bring spiritual support.*

*St Francis Hospice's home-base care satellite offices in Port Elizabeth are run by the careworkers on a day-to-day basis and host the project's day care. Some patients don't attend because of the stigmatisation attached to visiting the offices. Alternatively, these offices have been a starting point for patients wanting to come to terms with their HIV status but who do not yet wish to disclose to their families.*

### Debriefing

Caregivers generally meet as a group to discuss patients' health and social situations, often finding that most of the problems their patients face are social issues, for example physical abuse. Other concerns were that some of the patients had no-one to care for them at home and they generally live in dire financial circumstances.



Caregivers meeting at St Francis Hospice

Burnout for health care workers is not unusual because of the amount of high stress involved. Hospices have taken a proactive approach by providing various ongoing psychological support for caregivers. These include stress management classes, mandatory leave, and consultations with a psychologist.

*At South Coast Hospice, Port Shepstone, caregivers are given leave at least twice a year for two weeks at a time. They also meet with an outside psychologist once a month to help them deal with stress. In addition, every Tuesday the caregivers are given time to talk about clients who have died, sharing their experiences with the person, and addressing the positive and negative aspects of their care.*

## Volunteers

The integration of volunteers into the home-based care programme varies. Volunteers supplement the services provided by caregivers by supervising three to four patients in the immediate walking distance of the volunteers' homes.

*At St Francis Hospice, volunteer training is once a week for six weeks and is offered by one of the social workers at the hospice. The programme includes an orientation to the hospice, listening and communication skills, grieving and bereavement management, basics of home-based care, HIV/AIDS awareness and dealing with differences in religion.*

Volunteers are an integral part of the functioning of hospices in communities. They act as a vital contact with the communities, are well attuned to the conditions within communities and well-positioned to guide hospice towards social and cultural issues that need to be addressed. Living within the communities, volunteers are also a point of contact and referral. They are generally paid a stipend, or a volunteer incentive, to cover expenses.

Volunteers are variously motivated and their motivations include a mix of altruism and opportunity to learn new skills and the possibility of becoming employed. The gradual professionalisation of hospice from being a largely volunteer-based organisation to salaried staff with a much greater patient-load is certainly one of the major transitions that seems to have occurred in the hospices visited. There is a sense in which this transition is still very much in progress and models for the integration of volunteers seems to differ across contexts.

The use of volunteers is not without its problems, and clearly the people who are available as volunteers in communities most affected by HIV/AIDS are not well-equipped in terms of educational and working experience to rapidly learn what is required of them. The process of working with volunteers from communities not part of the original domain of hospice has demanded a socio-cultural shift, which appears to have provided great challenges and opportunities for learning. Hospices are in the process of making the transition to being community-based organisations and the problems attached to this include challenges in establishing management and record keeping systems, for example patient visit records; good culture of work; linguistic differences; relationship with volunteers and establishing models of relationships to volunteers and the community.

## 2. Quality care in the home

*'You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die.'*

*(Cicely Saunders, founder of hospice in the UK, quoted in Buckingham, 1983:6)*

People with all types of terminal illness can participate in the ICHC programme. In some areas, the majority of patients have AIDS, while in others, cancer is more prevalent. For example, AIDS makes up the vast majority of patients in Helderberg Hospice's home-based care programme. Some also have TB. Alternatively, the number of people infected with AIDS in Sungardens Hospice's home-based care programme is almost equal to the number of cancer patients. St Francis Hospice's programme is similar – about 48% of their patients are AIDS patients.

Caregivers are grouped in teams of two for home visits.

*During a day of home visits, the caregivers from Helderberg Hospice, Somerset West, saw a number of patients in different situations. They visited one man with a CD4 count of 14 who was very weak but could still walk around; a woman who appeared to be terminally ill when she was released from hospital but recovered rapidly once the caregivers helped her work out her family problems; and another woman who didn't have a pension or an identity book, whose boyfriend didn't know she had AIDS.*



*A patient's home, St Francis Hospice*

Tasks of a home visit include:

- ❑ distributing medication and vitamin supplements;
- ❑ teaching family members or neighbours how to care for the patient, including how to give bed-baths, how to lift the patient, mouth care and other basic skills;
- ❑ cooking for the patient;
- ❑ providing food parcels and items of clothing where necessary;
- ❑ making arrangements to transport the patient to the hospital for medical exams, physiotherapy or other services;
- ❑ educating the family and neighbours about HIV/AIDS;
- ❑ listening, supportive counselling, and providing human contact in the case of isolated people.

The situation of the patient is initially assessed by the caregivers and a supervising nurse, who decide upon a method of care based on the needs of the patient and family. The needs of patients in established communities differ from those in informal settlements. For example, in informal settlements, roads are difficult to travel on, there is no running water, sanitation is poor, and diarrhoea and TB are prevalent. In

some cases, patients have nobody to care for them at home between visits, so the neighbours take on the responsibility.

Caregivers usually see each patient once a week, unless there is a more urgent need for care. A supervising nurse accompanies the caregiver when a patient is in need of medication or clinical diagnosis.

*The home care teams from St Bernard's Hospice are reported to have made more than 10 000 home visits to over 2 000 patients in 2001.*

Certainly one of the strengths of the hospice ICHC model is that it has proven to be adaptable to given situations and in a resource-constrained environment. All hospices have had to 'make do' with limited resources, and much innovation has been occurring under the circumstances.



*Caregivers visiting a patient's home in a rural area outside East London*

### Symptomatic treatment

Providing relief from pain and other distressing symptoms is a key element of palliative care. Pain and symptoms may be treated with conventional medication, however, the availability of drugs and treatment for opportunistic infections is limited. Some home-based care programmes are able to dispense injectable drugs, morphine and antibiotics via either hospice or the hospital, while others are limited to distributing whatever vitamins or pain killers have been donated.

*The Zululand Hospice Association's medical care for AIDS patients is limited at the hospice, but caregivers have access to anti-fungals, vitamin therapy and pain killers such as Panado and morphine.*

*Pretoria Sungardens Hospice does not have access to medicine, therefore community patients must see a doctor at the hospital or clinic to obtain medication.*

Hospice is oriented towards delivering holistic treatment. Hospice recognises that some patients are likely to be treated by traditional healers for some period of their illness, and therefore traditional remedies are included in dealing with pain and

symptoms. Traditional remedies are especially important for patients living in rural areas, far from any health resources and with very little money.

*Caregivers from Zululand Hospice Association are advised and trained by a local indigenous herbal plant expert on the use of plants for treating minor conditions, such as using frangipani (local anaesthetic) for shingles; gokum (wild fig) for thrush; bulbine for nappy rash and Karposi Sarcoma.*

Where available, supplies for hygienic home care are also provided to families – for example, antiseptic soap for washing.

*A new patient receives a home care kit from Naledi Hospice caregivers consisting of gloves, a torch, black bags, a candle, a plastic apron, and basic medicines such as Imodium and Panado.*

### Care for children

The need for community caregivers to assist with the social support of children who are HIV positive, have HIV positive parents or who are orphaned by AIDS, is growing. In response, some hospices have incorporated the care and support of AIDS orphans and their caregivers into their regular home-based work. Others have created special palliative care programmes and day care centres for ill children. These programmes are proving to be effective in improving the quality of life of these children and providing respite time for their often elderly or weak care givers. Training for caregivers in the care and support of children includes bereavement care, play, art and music therapy, and developmental stimulation.



*One aspect of Naledi Hospice’s support for children and their families is the Sunflower House that offers day care four times a week for orphans, HIV positive children and children of patients who have been referred by caregivers.*

Children, especially orphans, may be emotionally, physically and sexually abused and have poor and stressful home situations. Various activities have been developed in home-based care programmes to provide psychosocial support for these children. Welfare support for children can include assistance with obtaining grants as well as foster or adoptive care.

*Three of South Coast Hospice’s caregivers are dedicated solely to the needs of orphans and potential orphans. Part of the support programme is the Memory Box Project in which children are encouraged to keep memories, such as photos or letters from their parent or parents, and important documents such as their birth certificates in a metal box, in an effort to assist them in the grieving process and remind them of their histories.*

## Benefits of home care

### Improved health of the patient

Caregivers proudly recount numerous stories describing the positive changes they have witnessed in many patients’ health. One reason for this is that there is someone there making sure that patients take their medication and following up on trivial changes such as a mild cough, before it becomes a serious health risk. Patients also appreciate that they can ask advice from someone they trust without having to travel to a clinic.

*A female patient in Helderberg Hospice’s home-based care programme was so distressed by a growth in her mouth that she couldn’t sleep. She was confused by it and worried that it was cancer. She was able to discuss this with the nurse and caregiver to allay her fears.*

*Another patient with St Bernard’s home-based care visibly brightened up when she was visited by Sister Veronica. She had lost the use of her legs and about two months ago, the caregivers thought she was going to die. Although the caregivers and Sister Veronica said her recovery had nothing to do with them, from watching the relationship between patient and caregiver, recovery is no surprise.*

### Identifying needs in the community

Home-based care can serve an important role in drawing people who have slipped through the cracks of formal health care systems into a network of care organisations.

*A staff member at Zululand Hospice Association explained: ‘We come across patients living in old pipes and in the cane fields. We had a patient we found in a large cardboard box with two children aged 9 and 11. The children had been living in this box for 4-5 months. Eventually we had them fostered. They had been kicked out of their community when it was known she was HIV positive and the fact that she was a common-law wife gave her little power in the situation. She was eking out an existence. Previously she had some history of sex work, and was one of those who came to seek her fortune from the paid workers in Richards Bay.’ When the mother died, the children were fostered with the help of welfare agencies in the community.*

Caregivers living in communities are able to identify people with needs and problems through social networks, as formal communication infrastructures often don’t exist.

### Breaking stigma

Caring for patients in their homes is a means of breaking the cycle of fear surrounding terminal illness. It increases the visibility of people with HIV/AIDS in the community, thereby encouraging the normalisation of the virus. Educating family members about

the transmission of HIV encourages discussion and understanding. Caregivers often include neighbours and other members of the community in the education.

When caregivers become known in the community, they can serve as a point of reference for questions or referrals. People approach them in the streets to be part of the home-based care programme or to point out the need of a neighbour, or for a referral to another organisation.

*When the supervising nurse from St Bernard's Hospice drives through the communities, people see her car, and shout and wave. When she stops at people's houses, passers-by come to greet her and see what she is doing. The nurse said that she was surprised at how accepting community members were of HIV positive people once they know their status and understood the disease. In her experience, putting HIV status out in the open encourages other people to step forward and help. This may be related to the fact that there is such a high HIV rate in the area and most people have been affected in some way.*

Identifying and caring for people living with HIV/AIDS can benefit both the family and community, but it can also lead to the perception that hospice is an 'AIDS organisation' and may result in people who are not comfortable with their status being known, to be identified as HIV positive. In some instances, patients have requested that caregivers meet them outside their homes or to leave their medicine at a shop nearby. Sometimes educating family members is not enough to make them understand and acknowledge the virus.

Caregivers from the Zululand Hospice Association said stigma is a strong and pervasive element of their work. Though they are trying to teach families to support sick members, sometimes they find that families remain in denial and despite attempts at education, may continue to ask the caregiver, 'He's so sick, when will he be better?' They often know that the patient is suffering from AIDS but are not willing to name it as such. Caregivers also said that they sometimes find that AIDS patients are isolated in a little room, kept away from the rest of the family. By modelling respectful care, caregivers impact on reducing stigma.

There may also be misperceptions about palliative care. Because caregivers deal with terminal patients, it has happened that they are seen as bringing death to the household.

*One caregiver at Pretoria Sungardens Hospice said she always emphasises to families that, 'We are not there to bring health.' There have been instances where the community has viewed caregivers as 'agents of death', that if the caregiver goes into someone's home, that person will soon die. Some patients even think they're going to die because the caregiver is there.*

### Limitations of home care

Caregivers generally live in the area where they work and should therefore be able to walk to visit their patients. However, as the number of patients has increased, so has the geographical radius caregivers must cover to reach them and walking is not always practical. For example, caregivers at Helderburg Hospice travel between 50 and 100 kilometres a day. Even with vehicle access, most caregivers spend the majority of their day travelling to patients.

Generally, the supervising sisters have access to a vehicle, but the availability of transportation for caregivers depends on the hospice. For example, caregivers from Zululand Hospice Association reach their patients on foot, taking up to an hour to reach one person's home. Alternatively, South Coast Hospice has 15 vehicles for its home-based care programme and each team of caregivers has access to a vehicle.

Most roads are unpaved and hazardous, particularly in wet conditions. Some programmes have tried to liaise with patients and conduct follow-up between caregivers and their supervising nurse over the phone.

Another limitation in meeting the needs of people who need home-based care is that although there are good care programmes, they are located in pockets and many areas continue to be without such services.



*Pathway to a patient's house, East London*

### 3. Strong relationship with health systems

A major objective of the ICHC model is to integrate the work of three institutions of health care: hospitals, clinics and hospice. This cooperation between health care providers is especially important for people with AIDS because, as their condition is chronic, they are generally sent home from the hospital and live without proper medical supervision. Some live alone and others live with family members who know nothing about caring for a terminally ill person. Caregivers play a vital role in these patients' lives by providing them with a continued link to health services. The home-based care programme not only continues the process of care outside of the hospital, but also limits the frequency of hospital visits by educating patients and families to recognise the symptoms of ill health, allowing them to care for the illness before it requires hospitalisation.

Mutually supporting services include referrals, medical support, donation of office space and psychological support.

#### Referrals

There is no policy for admission into an ICHC programme except that the patient has to want to be attended to by a caregiver. Patients are usually referred to a hospice's home-based care programme by a local clinic or hospital. Caregivers initiate the relationship with the referred patient at the hospital before the patient's release. Upon the patient's release, hospice transports the patient home. The provision of transport may save the patient the taxi fare home or a long journey on foot.

Other people are referred by organisations in the community, by neighbours or community members who have identified a need, or are self-referrals.

A team of caregivers is assigned to patients in a particular area and the number of patients depends on the number of referrals. Because of the increasing number of people with AIDS-related illnesses, this all-inclusive policy of admission means that caregivers have an increasing patient load.

*One team of home-based caregivers from South Coast Hospice has 133 patients in eight communities. This team of two people generally visits between 8 and 12 patients a day in one area, starting with the especially ill patients, but every patient is attended to at least once a week.*

*At St Bernard's Hospice in East London, each team of caregivers is meant to have only 25 patients, but most of the time they have around 40. Hospice management hopes this will change with the addition of volunteers, but has limited the number of patients that can be admitted into the programme.*

### Medical support

For many hospices, access to basic medication is limited and they send their patients to the hospital for services that the home-based care programme cannot provide.

*St Bernard's Hospice has a particularly good relationship with Frere Hospital, a local government hospital, especially with regards to medication. The hospice does not get all the medication their patients need so they take them to the hospital, or receive medicine from the hospital for patients.*

*Naledi Hospice has a strong association with the local clinic where one of their community caregivers work once a week.*

*Helderberg Hospice has a strong relationship with several local doctors who accept calls, even at night, if a nurse or caregiver needs advice.*

Policies of re-admittance are also important because patients with AIDS tend to relapse.

*South Coast Hospice's home care patients are guaranteed a number of services by the local Murchison Hospital, including counselling and support services for families of patients; priority status at the hospital pharmacy if they require drugs; and guaranteed readmission to the hospital if necessary.*

### Donation of office space

Some hospitals have set up direct links with hospices' home-based care programmes, offering office or ward space in their facilities. This can be in the form of a 'step-down' facility, which offers a similar service to hospice's in-patient care, but is attached to the hospital itself, serving as a transition from hospital to home/community-based care for people who are either not well enough to be sent home or are without someone at home to care for them. Patients are attended to by community caregivers and families are encouraged to begin learning palliative care skills during this time.

*A local hospital offered an underutilised ward to Naledi Hospice. The space is being used as a step-down facility, where patients who still need additional care after they are released from the hospital before they go home. It is under the supervision of a hospital nurse but completely managed by hospice. Sunflower House for children is also situated within the hospital grounds.*

*Zululand Hospice Association recently established a close working relationship with the local hospital. The hospital provided space within one of its rural in-patient facilities for hospice to run a respite unit where patients can stay for up to two weeks until their condition stabilises. This also gives families a relief from the burden of constant care and allows them to gather their emotional resources.*



### Psychological support

Another way the formal health care sector has supported hospice's home care programme is by supporting the caregivers themselves. This is important given the emotionally taxing work of a caregiver. It also reflects the wide-spread recognition of the value and burden of hospice work on the part of the community of health workers.

*Ngwelezane Hospital has a psychologist who offers support to the professional nurses and the Psychology Department at the University of Zululand supports the community care workers.*

### Limitations of the relationship

As has been discussed, hospice programmes vary with regard to the type of relationship they have with local health providers. This relationship is often facilitated by previous experience within the formal health service. Many employees of a hospice's home-based care programme formerly worked for the Department of Health or a government hospital/clinic, making their relations with these institutions easier.

*One supervising nurse for South Coast Hospice's home-based care programme had previously worked at a local clinic for three years. She continues to have a good relationship with the nurses there, which has benefited the referral system and facilitated the availability of medication to her.*

Historically, palliative care is not offered as part of basic training for doctors and nurses and they may therefore have a limited understanding of it. This contributes to a general lack of recognition of the importance of palliative care. Hospice may be perceived as historically associated with the white community, which may also hinder relationship building.

Staff at all home-based care programmes agree that a good relationship is difficult to establish and time consuming to maintain. For example, in some areas, there is competitiveness between hospice caregivers and nurses at hospitals or clinics.

The formal processes of health care institutions may be another obstacle to cooperation with hospice.

*Caregivers at Zululand Hospice Association said partnerships have been difficult to establish, because primary health care clinics have their own methods of operating, which are often not flexible. It has involved 'infiltrating their domain and trying to get them to change their routines' which has not been easy. 'They wouldn't part with their patients and*

*instead of getting involved at that level and thus preventing people slipping through the net, we had to catch them and put them into the system.’ Hospice has not been able to prevent problems at clinic level, but has had to act as a back-up by dealing with problems created at that level.*

Whereas early identification of patients is important, for various reasons most people who are referred to the programme are already in the terminal stage of AIDS and have only a few weeks to live.

*At South Coast Hospice’s home-based care programme, 85% of their patients are in the terminal stage of AIDS. This means that there is high turnover of patients.*

*The average period with St Bernard’s Hospice’s home-based care is four months.*

Most areas covered by home-based care are rural and may have limited access to HIV testing facilities, making HIV testing inaccessible or difficult.

Another factor related to the early referral of patients to hospice is the relationship of the caregivers to the nurses or counsellors and clinics and hospitals who are providing pre- and post-test counselling. If there is not a good relationship between the two, the patient may not be referred.

#### 4. Support networks in the community

The ICHC model of care is not meant to be only located in communities. Rather, it should be seen as an integral part of a wider care network. Hospice’s home-based care programme, other community organisations and local government departments can benefit at various levels by drawing from each others’ expertise and experience.

*There are a number of other home/community-based care initiatives in the Empangeni and Richard’s Bay area. There are efforts made to keep a good relationship with CBOs and NGOs that are also working in the field, including organisations involved in mental health and child welfare. There is good co-operation with Red Cross, especially in cases of trauma and crisis. Hospice is also involved in an umbrella body which looks at family care, mental health, empowerment and inter-sectoral health HIV/AIDS issues.*

*At St Francis Hospice, Sister Ivy works with a host of other organizations in the field including SOS Children’s Villages, AIDS Haven, PWA support groups and faith-based organizations. Sister Ivy feels that they have infiltrated the whole community through networking and partnership with other organizations.*

#### Sharing experience

The quality of care for people living with HIV/AIDS can be greatly improved through cooperation and sharing of experiences between organisations. A good network facilitates a link between homes and resources.

*There is a great deal of cooperation between NAPWA and St Francis Hospice. Hospice patients can be referred to NAPWA support groups and hospice-trained volunteers are used to take care of NAPWA patients until they come to the hospice’s programme.*

Networks of organisations can better deal with the diverse needs of people with HIV/AIDS.

*Each patient in St Bernard's home care programme has a link with another support organisation in the community. Many of these groups are not formal and there are no formal partnerships between hospice and these programmes, but a system of support is maintained through the common goal of caring for people with HIV/AIDS.*

*South Coast Hospice is working in conjunction with the Department of Home Affairs to address the situation of many people in the community of not having birth certificates. Hospice has hired two people to facilitate the process by travelling into the communities themselves and doing late registration.*

If organisations work cooperatively, the weakness of one in a specific area can be complemented by the strength of another. Organisations can improve their services through learning from the expertise and experience of others.

*The other organisations and groups of people involved with Naledi Hospice rely on hospice staff to guide them in how to care for terminal patients. They seem to have a lot of respect for the nurses, and are encouraged by the praise that the nurses give them for looking after the patients so well.*

*The Department of Psychology's Psychological Services Centre at Rhodes University in East London has a partnership with St Bernard's Hospice. The centre provides assistance in various ways, including the implementation of a counselling skills course for home-based care and other hospice staff; establishing a supervision group for home-care staff; running a support group for volunteers; working with terminally ill patients; and counselling bereaved families. The centre also places interns at hospice to provide training and supervision for the initiatives.*

### Sharing resources

By training people in other organisations, the work-load of hospice is kept to manageable levels.

*Staff at Naledi Hospice have become leaders and trainers in the East London area. At a meeting of all NGOs, CBOs, and FBOs in the area, hospice was elected to play the primary coordinating role. The ICHC model of care was chosen as the model for training. Sixty-four NGOs and CBOs are now linked with hospice and are taking part in ICHC training.*

*South Coast Hospice recently piloted a mentorship programme to empower organisations in the community with project management and home-based care skills.*

Community organisations, such as churches or women's groups, may also be involved in sharing physical resources that caregivers may not have access to, such as transportation or a venue for day care.

*Zululand Hospice Association has an extensive volunteer programme and is linked to many organisations. It receives support from local church groups and from Holy Cross Hospice which also runs a school, clinic and out-patient care. Hospice has its own vehicle, however it is not always suitable or adequate so a local church assists with transporting patients to the hospital or clinic when it is needed.*

### Limitations of support networks

As is true with relationships with other health care organisations, relationships with communities can also be very difficult to establish and strenuous to maintain. For example, there have been instances of competition between organisations with similar programmes.

*Caregivers from Helderberg report that there were conflicts between their teams and caregivers from another home-based care programme in the area, and that there was favouritism by the clinic in regard to referrals. This situation was solved when the other programme moved to another area.*

## 5. Continuum of care

Hospice care is based on the idea of holistic treatment, incorporating patients' physical, psychological, social and spiritual needs. As is depicted by the ICHC model, a continuum of care is provided for both the patient and family in various ways. Caregivers provide a number of services, starting at diagnosis with counselling, through to bereavement and beyond. Patients and their families enter in and out of the continuum at different times, depending on their needs.

It must be noted that as has been the case with other aspects of the ICHC model, the continuum of support is often limited because most people are only referred to the home-based care programme when they are in the terminal stage of AIDS.

### Physical care

The ICHC programme is intended to begin at diagnosis, providing counselling, nutrition and education preventive therapies, amongst others, and extends to appropriate care and treatment of opportunistic infections, as well as effective management of pain and symptom control. Caregivers also provide supervision of medication and are trained as DOTS workers to supervise TB treatment. They would also be ideally placed to supervise and support ARV treatment.

A continuum of support also must include issues related to poverty alleviation. In many of the areas covered by home/community-based care programmes there is massive unemployment. This has been addressed in various ways, including food and clothing distribution, training and income generation projects.

*In areas covered by South Coast Hospice, there is a 70% unemployment rate, and caregivers have had to establish ways of meeting patients' basic needs. As stated by Kath Defilippi, the hospice's director, 'It's pointless to administer painkillers when a patient is suffering from hunger.'*

*Staff at St Bernards Hospice organise food parcels for those in need, as well as the distribution of clothes, bedding and furniture – basically anything they think the patient needs or the patient has asked for. St Bernard's has a network of people who continuously donate necessary items to the hospice and if there is something specific that they need, they let people know. Word-of-mouth usually results in someone from the community coming forward with the request.*

Caregivers encourage maintaining hygiene and nutrition in order to prevent opportunistic infections, thereby sustaining the patient's life.

*Health and hygiene are important components of Pretoria Sungardens Hospice's day care and home care. Caregivers teach family members nutritious methods of cooking with foods that are readily available in the community, such as beans, spinach and potatoes. They also encourage the use of a 'tippy tap', a two litre bottle used as a tap to conserve water and*

*improve sanitation, especially in informal settlements where there is no running water, as well as at funerals.*

### Psychological care

Counselling starts at referral and can include anything from being a shoulder to cry on to advice on dealing with HIV status. Caregivers encourage patients' acceptance and disclosure of their status, which can enable them to cope in terms of positive living, planning for the future of the family and the placement of children. Caregivers also facilitate disclosure through education within the family and neighbouring community.



*Nursing sister from St Francis Hospice counselling a patient*

Caregivers are involved with both the patient and the family throughout the bereavement process. They provide counselling and upon the death of the patient the caregiver provides logistical assistance, such as informing the authorities of the death, assisting in the handling of the body, and arranging for the funeral and burial. Bereavement counselling for the family may continue several months after the patient's death.

### Spiritual guidance

While spirituality is generally considered a private experience, for many people it grows increasingly important towards the end of life. Terminally ill patients often experience intense questions pertaining to spiritual and other related issues, which may manifest as clinical suffering, and aggravate pain and psychosocial problems. The recognition and management of spiritual issues is an important part of palliative care, which is addressed by involving spiritual leaders in the day care programme and in home visits at the patient's request.

*One caregiver at Pretoria Sungardens Hospice said she works not only Monday to Friday, but every day as a hospice worker. On Sunday she attends church and teaches people about home-based care and how it*

*affects people's lives. She speaks at the funerals of her patients, and often people will come to her afterward and ask her how they can go about opening their own hospices.*

Respect for the patient's spirituality is essential, so hospices provide training for their caregivers on understanding different religions. This is facilitated by hospice's long history in dealing with the spiritual dimensions of living and dying.

### Social issues

While there are grants available for people living with HIV/AIDS, the process of accessing them can be difficult. Caregivers and social workers from hospice provide assistance in accessing welfare services such as disability grants, maintenance grants and pensions.

Even with the support of hospice, many people who need these grants are unable to receive them because of the application criteria.

*Sindizwa Ngwenze, Helderberg Hospice's Social Auxiliary Worker, helps patients to access disability grants. In her experience, it is difficult to receive a grant, even if a patient is in dire financial circumstances, because the patient must be in Stage 4 of AIDS, with a CD4 count of less than 200 in order to qualify. The criteria for the grant states that a patient must be terminal, but even when the patient has reached that point, he or she then has to wait another three months for the grant to process pay out. Sindizwa is discouraged by the number of patients she has seen die before they receive any money. Another obstacle to accessing a grant is not having an identity book, which is a common situation for many people in rural areas.*

Hospice also assists in the placement of children with other family members or neighbours if the parent is not well enough to care for them.

## 6. Bridging education and prevention

Providing information and options for families and community members is invaluable in HIV/AIDS prevention because it breaks the silence surrounding the virus. It makes people understand what is happening to so many people around them and allows them to do something to affect the situation. Hospices offer different forms of education for various audiences.

### Modelling care and education

Caregivers model respectful care during home visits. This makes the family less fearful of what is happening to the patient and gives them confidence because they can then properly care for the patient on their own. Sometimes, a patient's neighbours also become involved in some aspect of care.

*Caregivers in Pretoria Sungardens Hospice prioritise education for families in nutritious meals. They teach healthy methods of cooking, including stir fry as a way of maintaining nutritional value, which benefits both the health patient and the whole family.*

*Neighbourly care was evident in all the homes visited with caregivers from St Bernards Hospice. Sister Veronica said that when a patient is referred, she finds their house and gathers the neighbours around to give them a lesson on the basics of HIV – what it is, how you get it, what is going to happen to the patient and what the patient needs. In her opinion, this has*

*made a big difference in the way people respond to patients with HIV/AIDS. In one instance, an old retired man who lives across the road from one of the patients fetches water for the patient's household.*

Caregiver's education should reach beyond the family unit to members of the community, in an effort to promote awareness and acceptance of HIV/AIDS as a community problem.

*Caregivers at Pretoria Sungardens Hospice work with local traditional healers and herbalists regarding low cost alternative treatment. In addition, a number of traditional healers have allowed them to address their clients on various issues related to HIV/AIDS including HIV transmission, basic nutrition, identifying HIV positive children, and disability grants.*



*Caregiver visiting a patient, St Bernards Hospice*

### **Palliative training**

Some of the pilot ICHC sites, including Pretoria Sungardens, Helderberg and Naledi Hospices, host the Short Course in Palliative Nursing for Professional Nurses. The course is offered in each province and has South African Nursing Council recognition. All supervising nurses in a hospice's home-based programme have taken this HASA certificate course, but it is also offered to professional nurses in the formal health care sector. This is especially important in promoting understanding between health care institutions and hospice, as well as emphasising the need for palliative care. It is also a means of creating continuity of good palliative care in clinics and hospitals for hospice patients who attend clinics or hospitals for medication or care between caregivers' visits.

### **Nutrition course**

Pretoria Sungardens Hospice has created a train-the-trainer programme on nutrition to equip caregivers and other community health workers with good nutritional advice for patients and their families. Nutrition is of particular importance in boosting the immune systems of HIV positive people in areas where there is limited access to

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medication. The training programme consists of eight sessions on the immune system and how it is affected by HIV/AIDS; nutrition, reasons for and effects of poor nutrition; nutritious foods; food safety; cooking methods; uses of garlic and how to grow it; feeding infants and children; nutritional problems; and growing food. All of the caregivers at the hospice have been trained in nutrition, as have caregivers from another home care service in the area and a pastoral worker involved with home-based care. The manual for the course has also been distributed to other members of HASA to incorporate it into their standard programmes.

## Summary of key issues

### Emphases and orientations of ICHC pilot sites

It is important to note that each hospice's home-based care programme has a different focus based on its previous experience and geographic location. For example, Naledi Hospice has a strong programme to support children, while Pretoria Sungardens Hospice emphasises nutrition because hospice staff have years of experience in the area.

Differences between hospices that are less tangible but are as important lay in the actual implementation of the ICHC model itself, including St Bernard's emphasis on spirituality, Helderberg's emphasis on a strong relationship between caregiver and patient, and South Coast Hospice's ability to access vast geographical areas. Some hospices, such as Naledi Hospice and Zululand Hospice Association, have established positive cooperative relationships with community organisations and/or hospitals and clinics in the area, which has in turn benefited the success of their programmes and the quality of care for people living with HIV/AIDS in the community. Others continue to struggle with community dynamics.

In some instances, a hospice's strength can be developed in a way that can be used in other home-based care programmes to complement what they are doing. For example, Pretoria Sungardens Hospice has collated its training on nutrition into a manual, which has been implemented into their training programmes. While sharing information is useful, it is dependent on the availability of funding.

On the other hand, a hospice's focus in one area can also mean that it is weak in other areas. For this reason, while the ICHC model incorporates different levels of care and support, hospices may not be strong in every area, or may lack in an area altogether. For example, at one hospice, whilst there is a strong community support of the home-based care programme, the supervising nurse of home-based care does not offer psychological counselling to her patients because she doesn't feel that she has the expertise to do so. This is to the detriment of the goals of the ICHC model and can be assisted through sharing of resources. Much can be learned by looking at the different applications of ICHC in different contexts.

### The process of transformation

Caregivers have expressed that through hospice's involvement in home-based care, the community's perception of the organisation has moved away from that of a service for a 'white, elite' clientele, to seeing it as an accessible service for all. Caregivers also generally feel that the home-based care programme has influenced hospice to transform towards being an organisation that is more attuned to the needs of the broader society. That said, at most hospices, the majority of hospice staff continues to be white professional nurses and the component of black staff is largely lower ranked caregivers. Hospices have had to deal with issues of transformation and are demonstrating that there is much learning happening at this level, in and between the ranks of hospice.

This said, there have also been reports of racial dynamics by home-based care patients themselves. For instance, at one programme, there are a number of nurses involved in home-based care and while the white nurse has patients of all races, the black nurses have only black patients. Caregivers have attributed this arrangement as being dictated by the wishes of the patient, for example white or Indian patients request to

be attended to by the white nurse. These are issues that are part and parcel of the identity of hospice and that are reflected in different ways in most facets of South African social life. Because of the intimate and personal nature of hospice work, it is expected that cultural and racial issues might be raised. In all hospices, these issues are present and are being worked through and hospice's commitment to the well-being of patients has prevailed. It seems that whilst racial and cultural divides are in evidence in the workings of hospice, certainly there has been a dramatic transformation from the previous white middle class cancer patient focus.

### The commitment and compassion of caregivers

Although the job of a caregiver is difficult and the pay is low, the strength of the home-based care programme often lies in the kind of caregivers it attracts. In a few cases, supervising nurses have found their caregivers to be less reliable – for example, filling out their log books and asking their patients to sign them ahead of time – which may affect the quality of care provided for their patients. However, most caregivers demonstrate daily their compassion for people who are sick and spend much more time and effort than is officially required with their patients when it is needed. One example is of a caregiver at Helderburg Hospice, who was the original caregiver recruited for the programme. Her innate interpersonal skills have assisted her to manage difficult patients with compassion and to create strong relationships with patients and their families.

As was mentioned previously, the representative racial make-up of home-based care staff has been encouraged, but quality of care is generally the primary orientation for selecting staff.

*There is a white supervising sister in charge of Helderburg Hospice's home-based care programme. Some have questioned this in terms of the transformational aspect of the ICHC model. However, hospice management sees the success of a member of the home-based care team as being primarily dependent on being the right person for the job. There is a respectful relationship between the sister and the caregivers, and she is also able to avoid involvement in politics between caregivers or with other community organisations. She is able to maintain a professional distance with patients, keeping a step outside the caregivers' role of being a shoulder to cry on, but can speak enough Xhosa to understand what the patient's needs are.*

### Cost implications of the ICHC model

With both a good home-based care programme and readmission policy, there are cost saving implications for the formal health care system. Fewer beds are taken up in hospital by patients who can be referred to home-based care. For example, in Port Shepstone the average time that terminal patients spend in hospital has reduced from around two weeks to three and a half days.

While costs to the hospital are decreasing, the opposite is true for hospice and it has been debated as to how cost effective home-based care actually is. Studies in Zimbabwe and Zambia have found home-based care to be almost as expensive as hospitalisation. In one rural programme in Zimbabwe, the cost of a three-month illness spent at home with two visits per week equalled the cost of a 76-day stay in a district hospital (Russell & Schneider, 2000).

In South Africa, the cost to the hospital is R650 per patient per day in KwaZulu-Natal, the cost to the home based-care programme of a caregiver's visit is between

R30 and R35 per patient per day, no matter how long the visit, in areas where the caregiver can walk. However, this difference is misleading as it does not take into account the economic costs of the supporting framework that capacitates these caregivers. The total cost per ICHC patient with South Coast Hospice, between the period of 1 April 2001 to 31 March 2002, was R1 015 per annum. The cost in this area is probably higher than in other areas because it includes coverage of especially large areas and costs of the vehicles for transportation.

It seems the jury is still out on cost-effectiveness of home-based care. There are complex economic issues to take into account, including calculation of the marginal costs of expanding in-patient facilities in the absence of home-based care. There are also complexities involved in evaluating the costs of volunteers, who incur opportunity costs in providing services that should be included in economic analysis. A core issue at stake in terms of finances is the sustainability of the volunteer base, especially if hospice services were to expand. Volunteers are partly motivated by career-development interests and it seems likely that pressure to pay volunteers greater incentives is likely to increase the volunteer-force expenses.

### Sustainability of the ICHC model

As with other NGOs without core funding, hospice management constantly struggles with securing funds. Hospices in the ICHC pilot studies are operating on extensive budgets. For example, South Coast Hospice's total budget for 2002-2003 is R3.3 million. Naledi Hospice has a smaller budget, R422 000, but 74% was budgeted towards AIDS patients.

Many hospices expend considerable resources on fundraising. Many times, there is a specific staff person hired specifically for fundraising. Many hospices also have second-hand shops to raise money. While this can be seen as compromising the efficiencies of hospice, accessing consistent funding is essential for sustainability.

Also related to sustainability are volunteerism and the low pay of caregivers. Most programmes rely on low paid caregivers to do the bulk of the work and others plan on introducing volunteers as part of their home-based care programmes. But there is some financial uncertainty in investing funds to screen and train volunteers in order to improve effectiveness of care and support work if their work with the organisation is indeterminate.

Research has shown that programmes with inadequate or no funding found it difficult to maintain volunteer commitment in community-based care programmes (Russell & Schneider, 2000). The study showed a high turnover of volunteers, who once trained and without contracts, may withdraw their help at any time and move on to other opportunities. Programmes with successful programmes tend to recruit those who are well respected in the community, as well as provide some form of incentive, ranging from a monthly stipend or other small incentives.

### Providing home-based care in the context of poverty

The extent of poverty in AIDS affected households was striking during site visits and while modelling care and providing information on HIV/AIDS is important, that is not enough to consider it to be useful to patients and families. It is difficult for patients to stay healthy, or for their families to care for them properly if the main concern is putting food on the table. Most families cannot afford to sustain care that puts additional strain on household resources without the support of the home-based care programme. For example, Pretoria Sungardens Hospice has found that families are unable to put what they learn about nutrition and healthy eating into practice because they lack the money. Caregivers have therefore started to supplement

nutritional information with gardening skills and encouraging families to establish food gardens in the available space outside their homes or in an open space at a school. They teach creative solutions to the cramped environment such as growing in containers or tires. Hospice's home-based care programmes are designed to be flexible and creative in order to address the situation of poverty and to effectively meet patients' needs.

### Providing services where there is stigma

The stigma of HIV infection can make home-based care difficult. Disclosure can lead to the community rejecting the patient and the patient's family. Most programmes are known to be focusing on AIDS patients, depending on the area. Some potential patients have refused to be part of the programme because they would be labelled as having HIV/AIDS.

### Lack of recognition from the formal sector

People involved in palliative care emphasise that this form of care should be recognised as a professional clinical service by the formal health sector. Liz Gwyther, head of HASA, said that while hospital is perceived as being a professional service, hospice is seen as 'some nurses holding hands'. This can be due to the lack of training in palliative care by health care institutions and can result in difficulty establishing relationships with these institutions. Community caregivers span this divide, which is the very heart of the ICHC model. The work of hospice is to ensure that the dynamic tension between these competing demands does not collapse in either direction.

### Conclusion

Hospice has, in a relatively short space of time, been required to develop a response within the context of a burgeoning need for home-based care for AIDS patients in South Africa. In many respects, whilst the broad ethos of the hospice approach has been maintained, the challenge has been to extend existing approaches into new territory. In some hospices, existing systems and structures have been retained and underpin emerging response, whilst in others, systems, structures and infrastructure have been considerably realigned. As a whole, hospices are being transformed and expanded as a direct result of the emerging needs of the HIV/AIDS epidemic.

Transformation is never easy, especially where new ground is being charted and where human resources need to be managed, but the value of developing and working with models is that this allows transformation to be well-considered and systematic. At the same time, the ICHC model is flexible, and any part of it can be adapted to an individual home-based care need or situation.

Within hospice, new models of operation are evolving which incorporate diverse human resources and capacities, and in social and community contexts that are themselves changing, and in circumstances that are constrained by poverty and hardship. However, the underlying ethos of care provision – ie. caring for individuals and their families in all aspects – combined with an understanding of the community contexts, is maintained within the ICHC model. Hospices are integral to the developing response to HIV/AIDS, and the organisation has risen to the emerging challenges. However continued support is required from other roleplayers in relation to both its internal development and transformation, and in relation to its reach into the community.

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## Appendix 1: Site visit interviews

### **Helderberg Hospice**

- ❑ Individual interviews with Janice Atcheson, matron of Helderberg Hospice, and Sindizwa Ngwenze, social auxiliary worker.
- ❑ Home visits to patients with Sister Gill Wasserfall, head nurse for the ICHC programme, Emma van der Merwe and Estonia April, community caregivers in Macassar.

### **Naledi Hospice**

- ❑ Interviews with Joan Maston, director of Naledi Hospice; and Elizabeth Swartz, acting director.
- ❑ Interviews with Emma Belot, nursing manager; Betsy Torsius, financial manager; Mary O’Rielly, administrator; and Gloria Tsi and Estelle Medea, community caregivers.
- ❑ Informal interviews with community caregivers Betty Jabani, Yolande Waldek; Josephine Madiya, social worker; and George Swarts, counsellor.

### **Pretoria Sungardens Hospice**

- ❑ Individual interview with Sue Cameron, head of training.
- ❑ Group interview with community caregivers and ICHC nurses: Viola Mohase, Agnes Ratsoma, Rebecca Masango, Sister Ethel Makhafola, Cynthia Vena, Albertina Adams, Peggy Kgopa, Suzan Makhubela and Sonia Mahlabane.

### **Zululand Hospice Association**

- ❑ Interviews with Sister Murray and Anne Gates of Zululand Hospice Association; Dr Haselau, superintendent Ngwelezane Hospital, Jenny Rogers, Zululand Chamber of Business Foundation; Sister Hlongwane, ATICC.
- ❑ At Ekuphumaleni Clinic, interviews were conducted with a group of trainee caregivers; a group of caregiver trainers and Dr Bogard.

### **South Coast Hospice**

- ❑ Individual interviews with Kath Defillipi, CEO of South Coast Hospice; Maraliza Robbertze, senior social worker; and Mabuyi Mnguni, deputy director of programmes.
- ❑ Interviews with ICHC nurses Margaret Venda, Francisca Dladla and Princess Cale.

### **St Bernard’s Hospice**

- ❑ Visits to patients’ homes with Sister Veronica Kildase, the head ICHC nurse.
- ❑ Interviews with Barbara Gerber, manager of the hospice; Sister Evelyn Reed, nursing coordinator; Sister Portia Dyasi and Sister Anne Webster, home-based care nurses; and Bongwiwe Matiwane, social worker.
- ❑ Group interview with community caregivers Mkizwe Makinza, Nomonde Kaonto, Ivies Nombila, Sister Larci Bengu, and Dr Terry Carol, resident doctor.

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**St Francis Hospice**

- Interviews with Sister Betty Grant, deputy matron; Sister Ivy Appolis, home-care Sister; Tabisa Khatsha, social worker/community developer; and Sister Nunu Mkhombisa.
- Group interview with community caregivers Nomonde Ganya, Nomfundo Pokile, Xoliswa Msweli, Ntombekaya Labithi, Bukelwa Matebese and Vivian Manona.

## Appendix 2: Interview schedule for hospice site visits

### Objectives of site visits were to:

- obtain information on the ICHC on a case study basis;
- determine strengths and weaknesses of ICHC model;
- compare ICHC to other models;
- determine what the specific hospice does in this specific area and how this can be translated into different areas/regions;
- identify constraints/strengths;

### Logistical information

- Year established?
- Number of HBC clients?
- Number of staff – community caregivers, professional nursing staff, others?
- Serving which geographical areas?
- Running costs/budget?
- Caregivers' interaction with professional staff? Contract period? Burnout?
- Funding? Sustainability?

### Local information

- History of hospice in the area?
- Perception/myths of service? Visibility of hospice in area?

### Services provided based on main characteristics of the ICHC model of care

1. Quality care in the home, early identification and management of complications.
  - How is this early identification and management of complications done?
  - What about in-patient care?
  
2. Relieves provincial hospital of the burden of care.
  - How?
  - What has been the response of the hospitals/clinics?
  
3. Draws in & strengthens existing community-based care initiatives.
  - Which ones? How?
  - What are these organisations' responses to their involvement?
  - Does the community generally seem supportive of the hospice?
  
4. Trains people from the community as caregivers and provides them with jobs and personal support & supervision.
  - Community workers: Who is chosen? Are they paid? Training?
  - In what way does this benefit the hospice?

- ❑ What kind of relationship exists between professional staff and community workers?
  
- 5. Provides a continuum of support from voluntary counselling & testing right through patient care to bereavement follow up and family support following the death of the patient.
  - ❑ Is there stigma on families of patients who use this service?
  
- 6. Provision of palliative care, the control of pain and other symptoms, management of psychological, social and spiritual issues.
  - ❑ Are drugs provided?
  - ❑ Who/what is involved in the psychological, social and spiritual support?
  - ❑ Are in-patient facilities available for community patients?
  
- 7. Incorporates the formal and private health care sector.
  - ❑ In what way? Examples?
  
- 8. Links palliative home/community-based care to prevention, making use of the many powerful teaching moments whilst working with patients and their families.
  - ❑ In what way is prevention done?
  - ❑ To whom is it targeted?
  - ❑ How receptive is the audience?

**Specifics on the implementation of the ICHC model**

- ❑ Strengths/weaknesses of the hospice's programme
- ❑ Professional/personal experience with ICHC model
- ❑ Previous experience with other models of home-based care
- ❑ Strengths/weaknesses of ICHC model compared to other models
- ❑ Challenges of the ICHC model
- ❑ Lessons learned from experience
- ❑ Does this model encourage sustainability?

### Appendix 3: ICHC Pilot Sites

Name of Hospice	Year established	Average No. of ICHC clients	Number of ICHC personnel	Geographical areas covered	Hospice budget (2002-2003)	ICHC budget (2002-2003)
Helderberg Hospice <i>(Somerset West, Western Cape)</i>	1986	100	10 carers 1 sister 1 social aux worker 1 social worker	Macassar Nomzamo Lwandle	R1.8 million	R250 000
Naledi Hospice <i>(Bloemfontein, Free State)</i>	1989	200	6 carers 3 nurses 3 volunteers	Bloemfontein & surrounding areas	R2 million	R1.7 million
Pretoria Sungardens Hospice <i>(Pretoria, Gauteng)</i>	1987	285	13 nurses 17 carers 15 volunteers	Greater Pretoria	N/A	R560 000
South Coast Hospice <i>(Port Shepstone, KwaZulu-Natal)</i>	1983	562 adults 316 children	3 nurses 14 carers 3 child carers 85 volunteers	Between Mtwalume & Port Edward, inland to Harding	R3.5 million	R1.4 million
St Bernard's Hospice <i>(East London, Eastern Cape)</i>	1991	110	4 sisters 3 carers 20 volunteers	Greater Buffalo City	R1.8 million	R800 000
St Francis Hospice <i>(Port Elizabeth, Eastern Cape)</i>	1984	213	2 nurses 8 carers	Nelson Mandela Metropole, Kouga Region	R2.9 million	R1.6 million
Zululand Hospice Association <i>(Empangeni, KwaZulu-Natal)</i>	1991	200	5 carers 65 volunteers 2 nurses 1 social worker 1 administrator	Enseleni Msingazi Esikhaweni Ekuphumeleni	R600 000	R500 000

THE Integrated Community-based Home Care (ICHC) is being promoted by the Department of Health and the Hospice Association of South Africa as one of the models for developing community-based systems of care in response to the AIDS epidemic in South Africa. This report is based on a review of the activities of seven hospices in South Africa, that have been financially supported by The POLICY project in implementing the ICHC model.

The document discusses the similarities and differences between the hospice ICHC model and four other home-based care models used in South Africa. The distinctive element of the ICHC model is that it specifically includes a hospice as a coordinating and management body which works closely with local hospital and clinic facilities in providing services to people living with AIDS and their families, and does so primarily within the community. Hospice has a long history of providing palliative care to the chronically ill and dying and has a well established network of branches throughout South Africa. This has allowed it to rapidly develop ICHC programmes building on the foundations of existing infrastructure and experience.

The document provides details of the responses of seven hospices to the major elements of the ICHC model. The account is interspersed with reflections and experiences of ICHC caregivers and professional nurses involved with implementing ICHC programmes.

The core elements of ICHC which are examined in the report are: the training and use of community based caregivers; the challenges of providing quality care in the home in a range of socio-cultural contexts; the development of working relationships with a variety of health and welfare organizations and services; the establishment and development of support networks in communities; developing a continuum of care in contexts where multiple agencies are involved; and bridging the gap between education and prevention. One of the challenges running through all of these themes has been to provide a high quality of palliative care and to orient other service providers and care givers to the challenges of doing this.

The review shows that each of the hospices involved faces unique challenges in implementing ICHC. In responding to these challenges hospices have had to adapt to local conditions. Also, the challenges of providing ICHC in contexts of poverty has required much innovation and creativity. Adaptability has proved to be a major strength of the model, and derives from its primary emphasis on understanding and engaging with the needs of patients and their families, and engagement with other services providers in developing a continuum of care.

The implementation of ICHC has faced considerable challenges and many of these are ongoing. The report draws attention to the fact that not all hospices are strong in all elements of ICHC and focus on some areas in particular hospices has meant that other areas are relatively undeveloped. There are challenges of transformation within each of the hospices which in many respects reflect processes of transformation in South African society as a whole, and this poses an ongoing challenge. There are also challenges in developing ICHC in a context where demand far exceeds supply. The demand for ICHC services will continue to grow, perhaps exponentially, and attention needs to be paid to the question of whether hospices are geared to cope with this. Expansion in keeping with demand will require greater support for development of organizational and management infrastructure than is in evidence. There is a need to address mounting demands on management resources and to pay attention to transformation challenges within the closely-knit organizational cultures of small hospices. There is also a need to develop further understanding of the costs of the ICHC model against alternatives.

What is most notable and which perhaps best accounts for the success of hospices in implementing the ICHC model in adverse circumstances is the vocational attitude which seems to be integral to the model of functioning of hospice as an organization. Dedicated staff, ranging from highly trained professional staff, at all levels show a rich blend of professionalism and compassionate commitment to their work.