

## Chapter 40

***Starting and Managing a Hospice Organisation******Overview***

Almost all the existing hospice programmes in sub-Saharan Africa were started by health care professionals, as in the rest of the world. These energetic and enterprising individuals felt passionate about providing holistic care to patients whose pain and end-of-life needs could not be met by the conventional health care system. It is largely thanks to their determination and sense of missionary zeal that palliative care has become established and gained credibility and recognition.

From the beginning, hospice work has meant teamwork. The early pioneers were volunteers, responding with great resourcefulness, but usually without training or experience in management.

When the first programmes started in Africa, in the early 1980s, the majority of patients had some form of advanced malignancy (more than 98% in the authors' hospice). In the early 1990s, the HIV/AIDS epidemic began its inexorable and insidious growth and, by 2003, HIV/AIDS accounted for 90% of the same hospice's caseload, even though in real terms the number of patients with cancer also increased. The rapidly escalating need for hospice and palliative care has impacted dramatically on individuals, local programmes, and the growing number of national hospice organisations.

The HIV/AIDS pandemic will continue to shape the form of and demand for palliative care as well as its position in the formal health care sector (Defilippi, 2000). Enthusiasm and energy are essential for starting a community-based organisation or a hospice, but another 'E' also is needed for success: efficacy. That is the path we will walk with you in this chapter. The authors themselves have been mulling over and grappling with the way ahead, and look forward to sharing their experiences to help you get started and make your three 'E's' work.

***Authors***

Kath Defilippi

Anne Merriman

Audrey Penrose

Andre Wagner

***At a Glance***

Start-Up

Structure

Ongoing Management

References

***Starting and Managing a Hospice Organisation***

***Table of Contents***

Overview .....	535
Start-Up .....	537
Structure.....	539
Ongoing Management.....	543
References .....	545

**Start-Up**

This section assumes that you want to start a hospice home-based care programme and that you have validated the need in your community. Much of the information is based on the Hospice Palliative Care Association of South Africa (HPCA) document, which includes extensive guidelines. To obtain a copy, contact the secretary, HPCA, Cape Town, telephone: (021) 531 2094; e-mail: [hpca@iafrica.com](mailto:hpca@iafrica.com).

Always remember that if you need help, you can call for it. There are people who can and will help you get started. There are successful projects and resource people in many African countries — Kenya, Uganda, and Zimbabwe, for example — who are now moving into other countries to advise. See contacts in Appendix 1: Resources.

Whether to start small or big will depend on your resources and the prospect of sustainability. Most groups in African countries commencing for the first time will start small. But remember that education programmes and management issues need to be considered as well as the services themselves. Once these are in place, advocacy with government and other health professionals will be smoother.

***Starting Off on the Right Foot***

The first steps involve thinking about the hospice idea and planning it if you get agreement and buy-in from others to actually make it happen. Getting this kind of interest going to commit to an idea can be tough. It might involve getting a few people to lead the way. It also might involve identifying a given number of experts and interested people to sit down and think about the hospice idea and how to make it happen.

The first meeting will begin the building of a team based on cooperation and trust. It should have the widest possible community base. This gathering, properly guided and instilled with enthusiasm for your vision, will form the core of your hospice (see Box 40.1).

**BOX 40.1:**

***Holding the First Meeting***

***Planning***

- Fix a date for the first meeting.
- Aim to elect and appoint an auditor at the meeting.
- Ask each of the 'founding members' to invite other community-minded people.
- Try to get expertise in various fields — such as a friend from another hospice, nursing, business, legal, accounting, teaching, etc. Also try to involve those who may have simply expressed a desire to help — such as housewives, retired men and women, and in fact anyone who feels the need to do something to help those suffering in your area.

The first meeting should be fairly informal. Encourage participation and ideas but also respect people's time by keeping to the agenda and setting time limits for each item or speaker. A good chair will make attendees feel both listened to and productive. Be sure to take minutes.

***The Agenda***

To establish a business-like process and keep focus, prepare an agenda. You should identify a good leader in advance, someone who will chair this and subsequent meetings and keep the proceedings on track

An effective agenda might feature:

- Welcome address from the Chair
- Your 'vision' for the organisation, including community participation and involvement
- Areas of operation
- Initial venue and essential equipment, such as basic furnishings, computer, printer and software, telephone/fax, and stationery
- Acquiring start-up funding
- Attracting and retaining volunteers
- Deciding upon a name for the new organisation
- Allocating tasks and responsibilities by appointing committees.

Thank everyone for attending and commend them for their contribution and continuing willingness to help.

***Steering Committees and Boards***

If your first meetings are successful (and there may be many such meetings before you get things going), you will get interest in your hospice and start putting some things in place. This early start-up might be putting some ideas to paper. It might involve getting people who are willing to raise money—and actually go out and find resources. It also might involve doing something really small, like serving a single person and taking that informal idea and building from it.

Whatever first steps you take, you will need to create some oversight of your work fairly early on. This oversight group might even be your

first planning group. Whatever form it takes, you should draw up terms of reference for steering committee or board members as well as a paper on the spirit of hospice so that they understand the holistic and team approach. A paper on the ethos of hospice is available from Hospice Africa Uganda (Merriman, 1999).

Try to have a good mix of professional and business people who can offer management skills.

Be aware that a problem could arise if certain health professionals, who are specialists in their own right but not in palliative care, are on a board but don't understand the unique discipline of palliative care. They may use their own specialties' frameworks instead.

At the beginning, the committee or board will probably do it all. Over time, you will probably need to elect a steering committee to oversee more specialized work that is done by other committees. This steering committee also should attend to statutory requirements such as registering as a non-profit organisation and addressing tax issues and employment issues (e.g., worker's compensation and unemployment insurance) with the appropriate government agencies.

### *Constitution*

Prepare a constitution for the organisation. It should be clearly written and articulate an adaptable plan. The guidelines for the organisation's work should include:

- The aim of the group
- Types and conditions of membership and fees
- Extent of meetings
- How many form a quorum
- Officers, their roles and responsibilities, nomination, and election
- When the executive is installed
- Rules governing future alterations to the constitution

## Structure

### *Defining Organisational Structure*

In the beginning, you may have only one or a few staff members. They may even all be volunteers. Regardless, you need to decide very early on what services to provide. This will guide you as to what professional staff you need to employ or have access to, what volunteer input you will require, and what other structure you need to put in place.

Next you will need:

- An organisational layout with clear reporting lines (see Box 40.2: Developing an Organogram)
- Job descriptions and letters of appointments (see samples in Boxes 40.3 and 40.4)
- A volunteer database organised in terms of expertise and availability
- A volunteer policy that covers how the organisation manages, protects, and supports its volunteers (Hamilton, 2002)

Remember: Volunteers are the HEART of any community-based organisation. Treasure, nurture, and manage them!

### *Basic Policies and Procedures*

These will be added to from time to time, and should include:

- Financial management and accounting
- Media
- Ethics
- Human resources
- General, such as motor vehicles and worker's compensation

### *Lines of Communication*

Everyone in an organisation must know to whom they report and who reports to them. At the same time, each member in the team should feel free to express ideas and opinions. Hold regular staff and team meetings and make sure that everybody is kept informed. Make as much information as possible available to all. Openness will nurture trust and strengthen energy, enthusiasm and, thus, efficacy.

**Box 40.2:**

**Organograms**

**What is an Organogram?**

An organogram is a description of an organisation's structure which reflects different departments. It is often referred to as the map of the organisation that outlines the various level structures.

**Why the Need for an Organogram?**

Organisations need to clarify the roles of staff and identify, firstly, who their key players are and, secondly, how every other job title fits into the successful operation of the organisation.

Organograms also:

- Ensure that job functions, reporting, line management, and levels are defined correctly so that up-to-date job profiles can be put in place
- Assist with job planning and career pathing
- Help identify branching in or out of 'job families'

An organogram is an effective, easy reference tool which:

- Reflects the actual number of positions in an organisation
- Helps identify current staff
- Identifies new appointments
- Identifies vacancies

**How Do You Develop an Organogram Process?**

An organogram development process has two phases:

1st phase: Development of a functional structure that reflects the functions of the various elements of the organisation

2nd phase: Development of organisational posts to establish a structure for the organisation. This structure reflects the accountabilities and role designations of staff members and forms the basis for developing clear and specific job roles and profiles.

Defining the requirements for the organogram involves gathering information, which is sourced and studied carefully, and consulting to ensure correct application of the information. Each job role must be defined carefully, depicting the core functions of the job and the key role within the structure of the organogram.

Once the development process is complete and the organogram is finalised, it must be kept updated regularly as changes take place. The organogram is a vital tool as well as a flexible document that is used in times of organisational change and restructure.

**Box 40.3:**

**Job Descriptions**

Job Description	
Job Title:	Job Grade:
Department:	
Location:	
Name of Job Holder:	
Name of Supervisor:	
Date:	
Position in the Organisation: (use job title only)	
Supervisor: (1st Level)	-----
Supervisor: (2nd Level)	-----
This Position:	-----
Subordinates:	-----
Comments: (i.e., is there anything unusual about the above?)	
Other Important Contacts: (On work related issues, excluding the supervisor)	
Internal:	-----
External:	-----

**7. Job Specification**

(NOTE: This is a requirement that is set by the company and is to be completed by senior management. It is generally used for recruitment purposes.)

**7.1 Education**

(Formal education)

Min: \_\_\_\_\_

Ideal: \_\_\_\_\_

**7.2 Legal**

(e.g., drivers license, blasting certificate)

Min: \_\_\_\_\_

Ideal: \_\_\_\_\_

**7.3 Training**

(On the job training, should the present incumbent leave)

Min: \_\_\_\_\_

Ideal: \_\_\_\_\_

**7.4 Experience**

(Past career path that should ideally have been followed before attaining this position)

Job Title	Minimum Time Spent
-----------	--------------------

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

**1. Primary Purpose of the Job**

(One sentence, why the job exists. This should be unique to this job and not generic so that it fits other jobs in the organisation.)

**2. Major Task Headings**

**3. Adverse Working Conditions**

(e.g., dusty, lots of travel)

**4. Other Special Requirements**

**5. Salient Information/Parameters of Work Environment**

(This is optional, but is useful in showing parameters, e.g., budget size. This is particularly important to be filled in for the Director or senior management positions.)

**6. Detail Description**

(Start with a verb and avoid describing trivial or incidental tasks.)

Job Analyst's Name: \_\_\_\_\_

Job Analyst's Position Title: \_\_\_\_\_

Seen by Incumbent: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Agreed by Supervisor (1st Level):

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Agreed by Supervisor (2nd Level):

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Box 40.4:**

**Letters of Appointment**

A letter of appointment should include the following:

- Job title
- Starting date
- Salary and all benefits and conditions of service
- Information on induction/orientation
- Copies of the disciplinary code, contract, job description

***Cultivating Teamwork, Cooperation and Respect***

Teamwork forms the basis for the delivery of patient and family care services and for management. Much can be learned from reflecting on how a pride of lions operates: They form an awesome team made up of powerful, motivated individuals who work together to achieve clearly understood and realistic goals. The overall structure of the pride is flexible, reactive to need, and focused on the common good.

Similarly, the palliative care/hospice organisation should capitalise on natural talent and interests, cultivate good cooperative habits, and provide continual attention and training so that each member contributes to her or his maximum potential. To engender a spirit of trust, confidence, respect, and professional pride, you can instill such management habits as showing sensitivity to individual situations, seizing ‘teachable moments’, developing skills and opportunities and recognising achievements. This will enhance efficacy and job satisfaction. Remember, ‘The pride is more powerful than the sum of the strengths of its individual members’ (Thomas, 1992).

***Record Keeping***

**Clinical:** Records from all programmes form the baseline data on which every organisation needs to build. Ensure that everyone involved in a clinical capacity is ‘record oriented’ by making it clear that the very existence of the organisation depends on their input.

**Administrative/financial:** Every organisation in this area needs to be seen as transparent and of the highest integrity. A knowledgeable volunteer or staff member would be of inestimable value.

***Statistics***

From inception, the collection and dissemination of statistics is vital. How can one go forward without a record of what has or has not been achieved? Statistics provide to management the indicators vital in making informed decisions. Believe in your statistics, and devoting time and expertise to this task will benefit your organisation in many ways. Again, if you need help, call for it.

## Ongoing Management

This section is about being open to, managing, and coping with change.

### *Strategic Planning*

Also known as scheduled forecasting, this important function should be the focus of your board and a regular annual exercise. If one of your board members is an experienced facilitator, use him or her for this function. You could also invite people from other more established palliative care/hospice organisations to help with your thinking.

Schedule an initial meeting, followed by an annual report back and discussion on what worked, what didn't, and what can be done about it. Pull your board together with this task. Their varied expertise and input should form the guidelines. The results of these annual meetings should be written up and distributed to staff and volunteers.

### *Accessing Funding*

**Financial forecast:** Your initial strategic planning meeting should ideally incorporate a forecast from the finance department of what the running costs are likely to be for the next financial year.

**Budget:** After every financial year-end, the finance department, in discussion with management, should prepare a new budget. As the years go by, you will get a good feel for more and more accurate forecasting. These budgets or forecasts provide the impetus for the funding you will have to source.

**Grant writing:** Grant writing is becoming increasingly important to the continuity of projects (see Box 40.5) and should always be kept 'on the front burner'. You will need to select a skilled team of three or so people from your organisation who have good persuasion, presentation, and grant-writing skills. Each member of this team needs to have a sound knowledge of your organisation's activities and programmes, coupled with innovative ideas and a 'way with words'.

You need to provide possible donors with solid facts, backed up by statistics, successes, and goals attained as well as a good reason to provide the requested funding. All grant writers should be able to produce a viable workplan and matching budget. This requires both experience and skill, though skills in developing workplans and budgets can be relatively easily acquired. All grants need to be vetted by at least two members of the team, and certainly the budget must be checked by the finance department.

#### Box 40.5:

#### *Golden Rules of Grant Writing*

- Check the criteria of any prospective donor before embarking on an application for funding.
- Use the donor's forms if they are provided and make sure to include all the required information.
- Keep a schedule of the proposals (grants) written.
- Send required reports to donors on time.

### *Monitoring and Evaluation*

Each and every programme your organisation runs must be monitored and evaluated on a regular basis (see Chapter 39: Monitoring and Evaluation). An audit tool compiled by the Hospice Palliative Care Association of South Africa is widely used for evaluating community-based home care (contact the Association to obtain a copy).

- Donors need feedback from these audits, and they are invaluable in-house to incorporate lessons learned into the various programmes.
- Internal and external audits of the standards of clinical care are imperative and should always be welcomed, not as a criticism but as a learning process.
- Costing services, and ensuring that each department is aware of them, promotes optimal use of whatever human and material resources are available.

### *Gaining Credibility*

Everything the organisation undertakes should be dedicated to gaining credibility. Some of the particular ways an organisation can gain credibility are by taking every possible advantage of invitations to seminars and workshops, annual general meetings, networking partners meetings, and, most importantly, by forming bonds with other palliative care/hospice organisations both at home and internationally. Experience has shown that this leads to growth in all areas. In this way you and your organisation develop a sense of your part in the global team involved in this vital work.

Once established, your organisation can hold seminars, teaching programmes, and open days so that people are aware of your work. Enroll the help of relatives of patients you have cared for to help promote the human right for peace at the end of life and to emphasise that your organisation offers the skills to achieve it.

### *Growth and Development*

Vidal Sassoon once said, 'The only place success comes before work is in a dictionary'. Growth builds on success, and we all know we need to work to achieve this as individuals. Likewise organisational growth depends on many factors, including:

- Managing, and not venturing beyond, your limitations
- Consulting with others who have walked the path before you
- Having a respectful and invitational management style
- Building teams and being willing to adapt them
- Being open to change and suggestions from staff and others, because often those who do the job know the most efficient way to do it
- Developing skills and careers
- Nurturing staff and recognising their achievements
- Focusing on sharing skills in training and discussion sessions
- Setting up mentorship for newcomers with more experienced staff
- Ensuring that each member of the team stays focused on their task of care for the patient and family. When the pride is stalking a buffalo, it would be highly inappropriate for even a single lioness to chase after a warthog!

### *Sustainability*

This worrisome task confronts top management in every sphere, whether a business or community-based organisation. It is important to work at building respect and credibility locally, nationally, and internationally. The only way to do this is to conduct your affairs in a resolute manner, stay with your ideals and within your budget, and remain financially transparent. Remain true to your three 'E's' and remember the force of a pride of lions and remember that because hospice is a 'family'. Help and advice are always at hand.

## References

Defilippi K. 2000. Palliative care issues in sub-Saharan Africa. *International Journal of Palliative Nursing* 6:108.

Hamilton G. 2002. The support of volunteers. In Doyle D, ed. *Volunteers in hospice and palliative care — A handbook for volunteer service managers*. London: Oxford University Press.

Merriman A. 1999. *Hospice Africa Uganda: The hospice ethos*. Available from Hospice Africa Uganda, P.O. Box 7757, Kampala, Uganda. E-mail: info@hospiceAfrica.or.ug

Thomas I. 1992. *The power of the pride*. Singapore: Tien Wah Press.

