

## **LEARNING NETWORK**

# **Community Home Based Care Guidelines**

**Community Health Committee Training** 

**The Learning Network** is a collection of 5 civil society organisations based in Cape Town:

- 1. The Women's Circle,
- 2. Ikamva Labantu,
- 3. Epilepsy South Africa,
- 4. Women on Farms Project and the
- 5. Cape Metro Health Forum

The **Learning Network** serves as the umbrella body in the Western Cape and includes 4 higher education institutions:

- 1. University of Cape Town (UCT)
- 2. University of the Western Cape (UWC)
- 3. Maastricht University, in the Netherlands
- 4. Warwick University in the UK



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### **Community Home Based Care**

Community home based care sprung out of a need to treat patients at home. It pre-supposes that care-givers exist in the community or that a family member is willing and able to provide home based care. It also requires that care-givers have been trained on the basics of HIV/AIDS and community care.

Home Community-Based Care (HCBC) provides complete quality health services at home and in communities to help restore and maintain people's health standards and way of living by providing health services, supported self-care and health education at home.

HCBC offers services to people with:

- Physical impairment.
- Medication adherence support and counselling to people with chronic diseases including TB and HIV/AIDS.

Medication adherence support and health promotion prevents unnecessary hospital/clinic visits and admissions by reducing disease complications and deaths caused by chronic illness.

#### WHO PROVIDES HOME COMMUNITY-BASED CARE?

HCBC services in the Western Cape are provided by non-profit organisations (NPOs), which are tendered for and subsidised by the provincial government.

Patients who need ongoing care at home upon discharge from hospital are referred to a health facility at primary healthcare level in the area in which they live.

The dedicated Home Community-Based Services Coordinator at the clinic or primary healthcare centre refers the patient to the NPO partner responsible for HCBC services in the area. The NPO co-coordinator who is a nursing sister will assess the needs of the individual in their home and develop a care plan for them. The sister then assigns a community care worker (CCW) to the individual.

The care worker will render the service according to the instruction on the care plan and the sister will visit the individual to make sure that the plan is being carried through.

HCBC is not a 24-hour service and does not replace the family as the primary

caregiver. It is only meant to be a complementary and supportive service to prevent "burn-out" for family caregivers who are forced to care for sick relatives.

Clients needing community adherence support are, after having been educated on their health conditions, referred by the health facilities to Community Based Services for ongoing community support.

The Community Care workers also do health education to the households in the homes that they visit.

### TRAINING FOR COMMUNITY CARE WORKERS

Community care workers who work for the NPOs funded by the Health Department, have to complete a South African Qualifications Authority (SAQA) accredited Ancillary Health Care Qualification to ensure that they render a quality service to the communities and this is facilitated and funded by the Department of Health. Continuous, in-service training is provided by the Department of Health to ensure competence.

This service has not been implemented in all areas. The priority has been the uninsured population. Contact the District HCBC programme coordinators for information regarding the areas where it is available.

Western Cape: Tobeka Qukula Director of Community Based Programmes Tel: 021 483 2683 E-mail: <u>Tobeka.Qukula@westerncape.gov.za</u>

This essential elements of CHBC includes;

- 1. Providing physical, emotional and psychological care and support.
- 2. Care-givers should be trained on psycho-social aspects.
- 3. Establish a continuum of care.
- 4. A relationship should exist between the care-giver and the local hospital.
- 5. Develop a mechanism for educating the ill people, families and on-going care-giver training.
- 6. Ensuring adequate supplies and equipment e.g. medication, vitamins, sufficient nutritional food, a home based care kit which includes gloves, jik, black bags and other essentials needed in the care and treatment of AIDS patients.
- 7. Developing consistent and effective methods for monitoring and evaluation of the CHBC programme with various stakeholders.

In a table it would look like this;					
Category	Sub-category				
Provision of care	Pasic physical care				
Provision of care	Basic physical care Palliative care				
Cantinguage of a suc	Psycho-social support and counselling				
Continuum of care	Accessibility				
	Continuity of care				
	Knowledge of community resources				
	Accessing other forms of community care				
	Community coordination				
	Record-keeping for ill people				
	Case-finding				
	Case management				
Education	Curriculum development				
	Educational management and delivery				
	Outreach				
	Education to reduce stigma				
	Mass media involvement				
	Evaluation of education				
Supplies and equipment	Location of the CHBC team				
	Health centre supplies				
	Management, monitoring and record-keeping				
	Home based care kits				
Staffing and volunteers	Supervision and coordinating CHBC				
	Recruitment				
	Retaining staff				
	Staff development and incentives				
Sustainability	Budget and finance management				
	Technical support				
	Community funding initiatives				
	Encouraging volunteers				
	Pooling resources				
	Out-of-pocket payments				
	Free services				
Monitoring and	Quality assurance				

Evaluation	Quality of care – indicators		
	Monitoring and supervision		
	Informal evaluation		
	Formal evaluation		
	flexibility		

Basic physical care is the same as basic nursing care. It refers to ensuring basic nursing care and patient comfort. Care-givers should be able to recognize symptoms and refer appropriately in addition to having some knowledge of symptom management.

Basic needs such as food, shelter, comfort, care of bedding and clothing may require identification to ensure that home is the appropriate place where this care can be provided.

### Definition

**Palliative Care:** Palliative care is the combination of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life-threatening illness.

Such care attempts to meet the physical, psychological, spiritual and social needs of ill people and care-givers.

It requires a team approach including the ill person, family members, health and welfare workers and community volunteers.

Palliative care emphasizes living, personal choice, helping people to make the most of each day and maintaining a sense of hope.

It aims to improve the quality of life by relieving symptoms and enabling people to die in peace, with dignity and in keeping with their wishes.

### **Basic Nursing Care**

### 1. Universal precautions:

- hand-washing
- cleaning linen with soap and water
- ensuring a sterile environment
- using disinfectants and detergents
- safe disposal of rubbish
- avoiding contact with blood or body fluids

### 2. Positioning and mobility

- bathing
- Wound cleansing
- Skin care and oral hygiene
- Adequate ventilation
- And assistance with feeding in addition to guidance and support for appropriate nutrition.

### 3. Symptom management includes;

- · reducing fever
- · relieving pain
- treating diarrhea, vomiting, cough, mouth, throat and genital infections, tiredness and weakness
- neuro-physiological symptoms

### Basic HBC kits should contain;

- Basic medicines for pain and fever and wound treatment
- swabs, bandage, cotton wool
- multi-vitamins
- cleaning equipment, jik and cleaning fluids
- Protective equipment such as gloves or plastic bags and diapers.

# CHBC services also cover other essential spiritual aspects related to the patient dying. These include;

1. Anticipatory guidance: People often fear death and open discussion allows an opportunity to talk about these fears. Families often need help in discussing death and making plans for the future including placing of children who might be orphaned, memory projects and funeral plans.

- 2. **Inheritance rights**: Dying without a will often create some practical problems. Care-givers can help family members make rational rather than emotional or despondency based decisions.
- 3. **Bereavement Counselling**: Support and counseling to the patient and family is a very important aspect of CHBC. These should be continued for as long as necessary, especially the bereavement issues of children. Important elements of effective communication during this time include sympathy, respect, a non-judgmental attitude, empathy and a allowing for dignity to prevail.

### What is a Care-giver?

**CAREGIVER**: Primary care-giver who cares for the child.

**CARE-WORKERS**: Responds to child-headed households, primarily as a result of HIV/Aids. Visits the patient e.g. monthly or weekly.

**VOLUNTEER**: Runs programs in the community e.g. soup kitchen.

HOME-BASED CARER: Cares for the ill.

A care-giver in this context refers to the person who becomes responsible for the care of a child who is orphaned by HIV/AIDS. Caregiver could therefore refer to a grandmother, an aunt a neighbour or a person who has taken on the full-time responsibility of a child that has lost a primary care-giver.

The numbers of vulnerable children are growing daily. These are based on a number of reasons. As the HIV/AIDS pandemic grows or plateaus, we are left with a number of great challenges as a society. What happens to the increasing numbers of children? Added to this is an economic environment that is driving an ever-increasing wedge between the rich and the poor, leaving poor families to slide further down the survival scale.

It is currently estimated that approximately 12 million children have lost parents to the pandemic. In Africa, the effects of poverty, wars and family migration adds to the survival burden that children face.

It is estimated that sub-Saharan had approximately 48.3 million orphans at the end of 2005. (COPE evaluation).

Number of children in child-headed households receiving services from HBC projects, by province.

South Africa	85 242
Eastern Cape	18 037
Free State	1 760
Gauteng	3 398
KwaZulu-Natal	36 178
Mpumalanga	18 151
Northern Cape	463
Limpopo	2 811
North West	4 247
Western Cape	197

HBC Rapid Appraisal. 2003. National Department of Health

### **Essential Services**

- Early identification of children and families in need.
- Addressing the needs of child-headed households.
- Ensuring that the basic needs of families, children and sick parents, guardians are met e.g. food, shelter, education and alternative care.
- Linking families and care-givers with poverty alleviation programmes and services in the community.
- Providing families with information to increase their accessibility to grants and other financial support services.
- Providing counseling to address the psycho-logical needs of children and their families.
- Addressing discrimination, stigmatization and disclosures.
- Addressing capacity building needs of families and children.
- Ensuring coordination of the entire programme.
- Addressing burial costs especially for poor families.

• Addressing the needs psycho-social and economic needs of families losing a primary care-giver.

### The consequences of care-giver, home-based care interventions should include;

- 1. Household food security improved.
- 2. Receiving appropriate care and support
- 3. Receiving material assistance e.g. grants
- 4. Protection from life-damaging and life-threatening circumstances.
- 5. Ensuring multi-sectoral support such as; health clinic, schools, social services etc.

### Time-out for Care-givers

Because of the nature of care-giving work, it has a high burn-out rate. It is therefore important for care-givers to develop a regular support group.

Support groups ensure that;

- 1. We have a place to share experiences.
- 2. We are able to communicate our griefs to others who will understand.
- 3. We have a place for therapeutic support and advice.
- 4. Being a caregiver is a long-term commitment. For most people who take on the responsibility of providing care to someone with serious health issues, it's not a short-term commitment.
- 5. **Being a caregiver takes a toll.** Being a caregiver takes a toll on you physically and emotionally—and it can also create enormous financial pressures that add to your stress.

### **Types of support**

**Psycho-educational programs** -- These care-giver classes, which help care-givers, learn skills such as behavior management, depression management, anger

management, and personal care techniques, have been shown to reduce caregiver stress and enhance well-being.

**Care-giver support groups** – It is very important for care-givers to get together and have de-briefing sessions, at least on a monthly basis. These sessions will create opportunities for people facing similar challenges and with similar emotional consequences, to come together and talk through some of the challenges faced. It may be a good idea to develop a roster so that each person gets a chance to speak and the sessions have a rotating facilitator. This encourages personal growth and ensures that all care-givers, both the silent and more talkative ones, have an opportunity to off-load, share information and get feedback.

**Ongoing training** – The more informed we are, the more we are able to develop coping mechanisms. E.g. If we understand that some patients can go into a state of dementia in late stages of AIDS, we can learn to separate ourselves emotionally from some of the painful comments that can be made in a dementia state.

**Organisational Support Structure** – organizations that care-givers are affiliated with can also provide various opportunities for care-giver debriefing. This can be done in a structured manner in a planning session. Planning sessions could cover very important areas such as;

- Developing a care-giver kit.
- Therapeutic intervention.
- Assessing care-givers for work-load and burn-out.
- Ongoing skills development.
- Access to opportunities in the care-giving field.
- Review of financial support.

### **Documenting Results**

It is important to document results. Here are some of the results that you would need to document;

- No. of families served.
- No of children accessing the services.
- No. of clients served.
- No. of families/children accessing grants.
- No. of children remaining in school, broken down per gender.

The scale of the orphan problem means that extended family and community initiatives are currently carrying the full burden of this challenge that we face as a society. These initiatives provide valuable interventions that children require to avoid social crisis including parenting, protection, psycho-social support and material assistance.

But do care-givers have sufficient information, resources and access to therapeutic release in order to sustain the kind of support that they provide? With this care-giver guideline, we attempt to look at all the various levels of knowledge and support that care-givers require, in order to carry out their valued role in a consistent, sustainable and effective manner.

Caregivers in most instances do not only provide care to the child but also the family support that is needed in a family grappling with death and its consequences. Traditionally this role has been carried out by hospices in our community. The extent of the pandemic, however, has eroded our resources and many people, particularly those far from hospices and in rural areas, are now dying at home and dependent on the knowledge and care of community volunteers, caregivers and home-based-care workers.

### **Grant Application Processes.**

### Information adapted from SASSA website.

#### www.sassa.gov.za

- SASSA is the organisation that processes grants on behalf of the Department of Social Development.
- All applicants must have a 13 digit bar code ID. (Special circumstances will be considered and should be explained to officials at SASSA).
- Grants will be paid from date of application.
- Apply at the SASSA office nearest to where the applicant lives.
- Application forms must be completed in the presence of a SASSA official.
- When your application is completed you will be given a receipt. (Make sure you have a receipt before leaving).
- It is permitted for family members to apply on behalf of an applicant who is too sick to travel, providing you have all the necessary documentation (See below).
- No money is charged.
- Approval will receive written notification of approval.
- If approval is not granted you have a right to appeal to the Minister for Social Development, in writing. The appeal must be lodged within 90 days of receiving written notification.

### 1. Disability Grant

- 1. Must be a South African citizen/permanent resident or refugee;
- 2. Must be a resident in South Africa.
- 3. Must be 18 to 59 years of age if a female and 18 to 62 years of age if a male.
- 4. Must submit a medical/ assessment report confirming disability.
- 5. Medical assessment must not be older than 3 months at date of application. and spouse must meet the requirements of the means test.
- 6. Must not be maintained or cared for in a State Institution.
- 7. Must not be in receipt of another social grant in respect of him or herself.

### 2. Child Grants: Foster Child Grant

1. The applicant and child must be resident in South Africa;

2. Court order indicating foster care status;

3. The foster parent must be a South African citizen, permanent resident or refugee.

4. Child must remain in the care of the foster parent(s)

### 3. Care Dependency Grant

1. The application must be South African citizen or permanent resident;

- 2. The applicant and child must be resident in South Africa;
- 3. Age of child must be under 18 years;

4. Must submit a medical/assessment report confirming permanent, severe disability;

5. Applicant and spouse must meet the requirements of the means test (except for foster parents);

The care-dependent child/children must not be permanently cared for in a State Institution; *Note: The income of foster parents will not be taken into consideration.* 

### 4. Child Support Grant

1. The primary care giver must be a South African citizen or permanent resident;

- 2. Both the applicant and the child must reside in South Africa;
- 3. Applicant must be the primary care giver of the child/ children concerned;
- 4. The child/children must be under the age of 15 years;
- 5. The applicant and spouse must meet the requirements of the means test;
- 6. Cannot apply for more than six non-biological children
- 7. Child cannot be cared for in state institution.

### 5. Grant-in-aid

1. The applicant must be in receipt of a grant for Older Persons,

2. Disability grant or a War Veteran's grant, and require full- time attendance by another person owing to his/her physical or mental disabilities; •

3. Must not be cared for in an institution that receives subsidy from the State for the care/housing of such beneficiary;

### 6. Old Age Grant

- 1. Must be a S.A. citizen.
- 2. Must be resident in S.A. at time of application.
- 3. Male must be 65 years old.
- 4. Female must be 60 years old.
- 5. Spouse must comply with means test.
- 6. Must not be cared for in a State institution.
- 7. Must not be in receipt of another social grant.
- 8. Must submit a 13 bar digit identity document.

### **Proof of Identity**

Applicants who do not have 13 digit bar coded Identity Book, or birth certificate for children involved in the application can still apply for a grant. Please obtain information from your nearest SASSA office on the alternative documents which are accepted for grant applications.

### **Methods of Payment**

You can receive your grant by the following methods:

- Cash payments
- Banks
- Institutions

Note: If you are unable to collect the grant yourself you may nominate a procurator to collect it on your behalf.

### Amounts of Grants as At 01 April 2014

Grant Type	Amount Payable 2009	Amount Payable – 1 <sup>st</sup> April 2014
Old age	R940.00	R1 350.00
		(over 75) R1 370.00
Disability	R940.00	R1 350.00
Grant-in-aid	R210.00	R310.00
Child Support Grant	R210.00	R310.00
Foster Care Grant	R650.00	R830.00
Care-dependency grant	R940.00	R1 350.00

Below are contact details for CT. Please go onto the website to get your local SASSA office details.

### Local offices:

Office	Address	Postal Address	Tel:	Fax:
Athlone	Melofin Centre, Klipfontein Road.	Private Bag X11, Athlone. 7760	021 696 8038/9	021 696 8072
	Athlone			
Bellville	Omnia Building,	Private Bag X50,	021 940 7100	021 948 3024
	107 Voortrekker	Bellville. 7535		
	Rd. Bellville			
Gugulethu	C/o Bishops Court	Private Bag X11	021 638 5151	021 638 5117
	& Fezeka,	Athlone. 7760		
	Gugulethu. 7760			
Khayelitsha	Julius Tsholo	Private Bag X001,	021 360 2100	021 364 1337
	Street, next to	Khayelitsha. 7783		
	Khayelitsha station.			
Mitchell's Plain	45 Alpha Street,	Private Bag X10,	021 370 4800 or	021 376 1342
	Wespoort Park, MP	Mitchell's Plain	4872	
	Industrial Area			
Wynberg	Cnr Maynard &	P Bag X25,	021 710 9800	021 710 9800
	Station Rd,	Wynberg. 7824		
	Wynberg	_		
Cape Town	48 Queen Victoria	PO Box 131. CT.	021 - 481 9736	021 423 8331
(Head office)	Street, CT.	8000		

### Social Relief

Social Relief of Distress is a temporary provision intended for people in urgent need of support because they are unable to basic food needs for their families.

Criteria:

- The applicant is awaiting permanent aid.
- The applicant is declared medically unfit to work for a period of less than 6 months.
- The breadwinner is deceased and insufficient funds are available.
- The applicant has been affected by a disaster, but it has not been declared a disaster area or
- The applicant has appealed against the suspension of his or her grant.
- The person is not a member of a household that is already receiving social assistance.
- The person is not receiving assistance from any other organisation.

Social relief of distress is issued monthly for a period of three months. Extensions may be granted in exceptional circumstances.

### Means Test

SASSA uses a means test to evaluate the income and assets of the person applying for social assistance. This test is the method used to determine whether a person qualifies to receive a grant. The means test varies from one grant to another.