NATIONAL GUIDELINE ON HOME-BASED CARE (HC) COMMUNITY-BASED CARE (CC)

DEFINING HOME-BASED CARE (HC) AND COMMUNITY-BASED CARE (CC)

WHO definition

Home care is defined as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death. Home care services can be classified into preventive, promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories.

It is an integral part of community-based care. Community-based care is the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities.

BACKGROUND

Home-based care calls upon the resources, skills, time, energy and funds of communities and governments. It is implicit that "health" is the outcome of the overall social and economic development of the community. Therefore, no single entity is able to meet the total requirements and challenges of home-based care. A collaborative effort is fundamental to success. Care in the community must become care by the community.

Rationale for HC

Due to the AIDS epidemic the increase in non-communicable diseases, the complications thereof and an ageing population's impending impact on communities, and South Africa as a whole, it is necessary to consider how best to provide care for healthy people, people with disease and their families. As more people become ill, many will not be able to stay in hospitals, hospices or other institutions for care.

It is also recognised that South Africa has limited health care resources. Situations will arise where, even if hospital or other institutional care may be the best response to an individual's condition, it may not be available to him/her.

The reasons for this include:

- Shortage of hospital beds.
- Inadequate number of medical, nursing and allied health professionals in the public sector.
- Lack of resources for treatment and drugs.
- Increasing demands of curable conditions on existing institutional care.
- Hospitals, which are crowded and over-stretched, are often unsuitable for managing patients with terminal or long-term diseases.
- Cost of institutional care.

HC will provide back-up for people, who need extended care, not necessarily hospital care or patients that are discharged early from hospital. However, HC is not intended to be “second class care” or “cheap care” for those who cannot afford hospital care.

- Commonly occurring diseases/conditions can be effectively managed at home
- Institutionalised care is not the most appropriate care for many problems.

Whom does the programme assist?

People who need basic support services to continue to live and/or die in their community and without which they would have been either prematurely, inappropriately or unavoidably moved to institutional care.

The programme shall be directed to:

1.
   - healthy people
   - at risk or frail older persons
   - at risk people with moderate to severe functional disabilities
   - people recovering from illness, in need of assistance e.g. post deliveries or after specific treatment.
   - terminally ill persons
   - persons living with HIV/AIDS or any other debilitating disease and/or conditions e.g. mental illness, substance abusers
   - any other disadvantaged group/person in need of such care e.g. people in crisis

2. and the caregivers of these people
   - families
   - caregivers from the formal system e.g. professionals
   - caregivers from the non-formal system e.g. NGOs, CBOs. DPOs
   - caregivers from the informal system e.g. community health worker (CHW), volunteers, other community caregivers and church groups.

Principles of home-based care and community-based care

- Holistic: physical, social, emotional, economic and spiritual. Community needs, to be addressed, but integrated into existing systems.
- Person-centred: sensitive to culture, religion and value systems to respect privacy and dignity (community-driven, customer-centred).
- Comprehensive, interdepartmental and all-encompassing; preventative, promotive, therapeutic, rehabilitative and palliative (multi-sectoral involvement).
- Empowering and allows capacity building to promote the autonomy and functional independence of the individual and the family or caregivers. Leadership is from within the community.
- Ensure access to comprehensive support services.
- Cover total lifespan.
- Sustainable and cost-effective resource responsibilities to be identified and shared.
- Promote and ensure quality of care, safety, commitment, cooperation and collaboration.

- Allow choice and control over to what extent partners will participate.
- Recognise diversity.
- Promote and protect equal opportunities, rights and independent living.
- Specific in what needs to be done and achieved.
- Focus on a basic and essential component of PHC.
- Adhere to a basic principle in health care and development, namely community involvement.

Purpose for including community-based care and home-based care into the PHC strategy.

- Prevention, early identification, as well as care and rehabilitation at community level will prevent the need for expensive institutional care.
- To reduce the pressure on hospital beds and other resources at different levels of service.
- To reduce and share cost of care within the system. Feelings of ownership and accountability are evoked.
- To allow people to spend their days in familiar surroundings and reduce isolation.
- To promote a holistic approach to care.
- To create awareness of health in the community.
- To put care providers in touch with potential beneficiaries/partners.
- It links and complements existing health services.
- To be pro-active rather than reactive.
- To allow the right to decide about care within own environment.

Proposed generic roles and responsibilities of different stakeholders

Home-based care/community-based care cannot be accomplished by only one sector or one type of service. Health, education, social development, local government, traditional healers and leaders, churches, NGOs and the community all contribute to the care process at community level. One organisation should be designated the responsibility to manage the care programme at community level (sub-district level).

Generic roles will be influenced by the model of service provision. The team may vary, depending on the resources of each community and clients' needs.

Formal system (doctors, nurses, psychologist, rehabilitation therapists, social workers)

- Identification of consumers, service providers and service priorities
- Overall coordination, planning and evaluation of services.
- A certain level of care - facilitation, mentoring, leadership, supervision, standards for service, codes for management of discipline and complaint procedures.
- Identify and agree upon resources to be available for service, including financial resources
- Policy development - management, accreditation and accountability structures
- Training, capacity building, advisory function and career planning.

- System support, e.g. referral system / follow-up system/caregiver support
- Create an enabling environment

Non-formal system (NGOs, DPOs, CBOs, FBOs and traditional healers and leaders)

- Identify community priorities and needs - including financial needs
- Outreach to members of community (networking)
- Operational coordination, planning and collaboration
- Monitoring and evaluation of service patterns, quality of care, consumer satisfaction
- Optimisation and control of available resources
- Advocacy and lobbying for services and resources - advise formal system
- Negotiations with other sectors
- Development of care plans to ensure continuity of care
- Direct care - preventive, curative, therapeutic, rehabilitative and palliation
- Support to caregivers and capacity building
- Leadership
- Identification of consumers and service providers
- Dealing with suspected abuse, disciplinary measures, complaints
- Referrals

Private sector

- Private sector should encourage medical aid schemes to contribute to the cost of home-based care.
- Intervention to fill identified gaps in service delivery, e.g. financial assistance, service delivery etc.

Informal sector (families, CHWs, volunteers, caregivers)

- Preventative care - growth monitoring, food security, disease prevention
- Basic care, basic rehabilitation, hygiene and safety
- Support to client
- Counselling
- Health promotion, education and therapeutic education
- Emergency care
- Referrals
- Household assistance

Client/Consumer

- Create a safe working environment
- Non-discriminatory treatment of carers
- Respect for carers
- Open communication related to working arrangements

GOALS AND OBJECTIVES OF HOME-BASED CARE

- To shift the emphasis of care to the beneficiaries - the community
- To ensure access to care and follow-up through a functional referral system.
- To integrate a comprehensive care plan into the informal, non-formal and formal health system.
- To empower the family/community to take care of their own health.
- To empower the client, the carer(s) and the community through appropriate targeted education and training.

- To reduce unnecessary visits and admissions to health facilities.
- To eliminate duplication of activities and enhance cost-effective planning and delivering of services.
- Be pro-active in approach

ADVANTAGES OF THE HOME-BASED CARE AND COMMUNITY-BASED CARE

- Reduce the pressure on hospital beds and other resources at different levels of service.
- Reduce and share the cost of care within the system.
- Feelings of ownership and accountability are evoked.
- Allow people to spend their days in familiar surroundings and reduce isolation.
- Enable family members to gain access to support services.
- Promote a holistic approach to care and ensure that health needs are met.
- Create awareness of health in the community
- Bring care providers in touch with potential beneficiaries.
- Intervention is pro-active rather than reactive.
- Right to decide about care within own environment.
- Commonly occurring diseases/conditions can be effectively managed at home.
- Promotes job creation especially in non-formal system.
- Decision making is inclusive
- Beneficial to family and friends as it allows more direct time with clients and involvement in care giving.
- Care will be individualistic and person centred.
- Avoid unnecessary referrals to and from higher levels.
- Avoid unnecessary and/or prolonged admission to

health care facilities or institutions.

- Ensure that partners in caregiving know and play their roles to avoid duplication.
- Ensure that caregivers and all key role players are well informed (knowledgeable), received adequate skills training and utilise other partners in care.
- Caregivers are fully involved and informed about the individual care plans.
- Ensure adequate documentation and encourage proper use of recorded information.
- Ensure continuity and consistency in service, quality assurance and management.

CHALLENGES OF HOME-BASED CARE

- Social environment is restricted - set believes and customs, ideologies and local conflicts, inappropriate housing.
- Emotional and physical strain and stress experienced by caregivers.
- Insufficient empowerment of clients and caregivers regarding care/resources and diagnosis.
- Uncertainty about the duration of the situation.
- Inadequate support structures for the caregiver.
- Dependency - allows for dependency of the client.
- Social isolation, related to confinement of the person to bed and the home.
- Emotions such as rejection, anger and grieving.
- Economic constraints and exhaustive care needs.
- Focus too often on health service activities only - no common vision.
- Fear or mistrust of the primary caregivers.

- Barriers to access built environment, communication and information.
- Poor resource allocation, e.g. respite centres/care, equipment.
- Lack of and confusion around volunteerism.
- Negative past experiences.
- Programmes are not community driven and fragmented.
- Emphasis on “sick” role and “disabilities” rather than on “quality of life” and “abilities”.
- Self-neglect - often refusal of intervention/care.
- Level of readiness of communities to accept their roles and functions.
- The concept of partnerships is misunderstood e.g. government is the sole provider.
- Confidentiality of diagnosis - unwillingness to disclose.
- HIV/AIDS epidemic will decrease caregiver pool.

THE THREE PILLARS OF HOME-BASED CARE AND COMMUNITY-BASED CARE

(i) Integrated management and referral service organisation

(ii) Training and development of community personnel and professional/technical support personnel.

(iii) Integration into the district health system (decentralisation).

Community service providers to identify -

- home-based care coordinators
- members of the HC/CC team
- training coordinator
- key care provider
- mentor/supervisor
- resource responsibilities including the budget

Establish the need for a home-based care and community-based care services and develop a community and resource profile. This can be achieved by conducting a community and/or family session.

Involve consumers to enhance productivity, initiating creativity and self-reliance.

“Piggy back” on existing, acceptable services and priorities.

Develop functional management and continuous, linked and uninterrupted referral system.

The broad objective is to establish an effective referral system at all levels, i.e. hospital, clinic and community and/or home.

The responsibilities of the referring facility are to:

- discuss with client and family home-based care/ community-based care as an alternative and obtain consent/agreement and acceptability based on informed decisions;

- assess clients' readiness for referral;
- inform the home care provider to which the client is being referred to, to allow notification and preparation to receive the client;
- provide written or pictographic instructions on medication, purpose for use and dosage;
- observe the understanding of the caregiver and/or client of the usage of medication;
- send a referral form to the primary care site that will take over the care of the patient;
- inform client and/or caregiver of follow-up care, appointments, details on patient-retained card, etc.;
- advise on any specific care, e.g. nutrition, hygiene, oral health, pain control, infection control, mobility, wound care,
- give contact details of the referral roleplayers as well as primary roleplayers;
- provide assistive devices, e.g. mobility and/or selfcare aids as required;
- provide pharmaceutical supplies and dietary supplements as required;
- provide sick leave certificates, social assistance forms;
- arrange transport for patient to home on discharge and for referrals;
- define formal/informal/non-formal partnership and lines of communication by contract or agreement;
- referral from community level should be accepted by the recognised referral facility.

INTEGRATED COMMUNITY BASED SERVICE (Annexure A)

Demographics	Number of people in need of HC/CC age, gender, race, health profile, etc. of population
Resources	Assess existing resources, e.g.: • Community contribution/ability to provide service • Home care services • Transport services • Facilities for respite care • Day care centres and community centres • Feeding schemes for children and adults • Libraries • Churches and religious groups • Mobile clinics • Clinics • Health technology • Financial resources • Human resources • Hospitals/institutions • NGOs, CBOs, DPOs, traditional healers and leaders • Other role players/service providers • Safety and security services • Support systems
Needs	Assess the needs for, e.g.: • Family support • Support for clients/care givers • Respite care • Training of family members and core care givers (care provider empowerment) • Perceived needs of community • Needs of individual client (Refer to Annexure B for assessment format)
Social Issues	• Community cultural beliefs and practices • Cultural, economic, social factors and community organisation • Community involvement levels/awareness levels • Individual capacity for self-care • Community performance/readiness/coping mechanisms • Communication system