

**Caring for Carers**  
**National Catholic Nurses Guild, La Verna, May 2007**  
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**Care of the sick and those affected by AIDS**

Care and support is at the forefront of the Church's response, one that calls on care-givers to be in it for the long haul, and beyond the call of duty. Religious women and Catholic nurses spearhead the Church's response to AIDS on our continent; take them out of the equation, and the Church's response to AIDS would largely collapse. By and large women bear the burden of the AIDS pandemic, caring for their own sick family members as well as for neighbours, and often also taking on the care and support of children affected by AIDS. Most people still in South Africa who need treatment are not receiving it and are dying untreated. Care-givers carry the emotional and psychological stresses of coping with so much sickness and dying. Some care facilities have an average rate of more than one death per day, and most people who are dying are young. Traditional African healing alongside (sometimes in conflict with) western forms of healing needs to be addressed.

Care for the sick is often extended to become care for children and families affected by AIDS since the care of orphans and widows is seen as something the Church has always felt called to. And yet so many more children in child-headed households need support, as do those in day care or in residential care. Psycho-social support for children takes care and support beyond the basic need for food, clothing, housing. Basic security needs are often addressed more readily than are needs for psycho-social support. Children are cared for by family members, in adoptive families, in various kinds of child care facilities. Traditional security nets and social systems are not coping. Many children fall through the cracks, while many other children are quite resilient; as Church and society though we owe them more than often we provide.

**Scripture: Come you who are blessed**

*"Then the King will say to those on his right, 'Come you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in. I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me.'"* (Mt 25: 34-36)

**Scenario 1**

- A group of several care-givers visits the home of an elderly man living with AIDS in a rural village. The man is sitting on a grass mat on the concrete floor of a two-roomed house. Children are playing outside, the eldest possibly about 12 years old. There are no adults apart from the old man present, although the children talk of a grandmother who looks after them. The children do not look neglected, but

the home is clearly a poor one. In the room where the old man is there are a few humble possessions, and a little bit of food. The house has electricity, but water has to be fetched.

- The care-givers talk cheerfully to the old man, while they sweep his room, and tidy up his few possessions. The children bring a dish of water, and the caregivers wash the old man who is on treatment for TB, and who has had a stroke. One arm and hand are partially paralysed. The care workers massage his body with vaseline, and make him comfortable. He doesn't want to take his TB treatment which he says tastes bitter. But when the tablets are crushed into a bowl of Morevite, a nutritional supplement, he eats well, unaware that he has taken his medication. He will need to go on ARV treatment some time in the future when his TB treatment is complete. He is quite a feisty character, with a sense of humour, but clearly unable to look after himself.
- When he has finished eating the care-givers gather round him and pray with him, reciting the familiar prayers of the Church, as well as praying for his special needs.
- The care-givers leave quite pleased with what they have accomplished. I have one lingering question to do with their being able to keep up both the TB treatment and later on the ARV treatment if the old man doesn't co-operate.

### **Pastoral Care**

People are hungry for the word of God and the healing mission of the Church and of Jesus continues to challenge individual people and whole communities today. We are challenged to make spiritual and pastoral care for those infected and affected by AIDS a priority in our church communities. Mostly pastoral care doesn't cost money, but we are often weak in the area that should be our strength. On the other hand sometimes home based care projects, day care centres for orphans, and treatment centers are like "house churches", another form of the local church where people can tell their stories and are listened to, where they pray for one another. Compassion, recognition, human dignity are the values that count.

Linked to cultural and religious taboos around death, sex, and linked to issues of shame and guilt we often find stigma, denial and discrimination which need to be challenged, in the Church as well as in society. Confidentiality issues are often confused with unhealthy secrecy/silence, and people keep silent when it would be more healthy for them to confide in someone they can trust. Stigma is an attitude towards people who are seen somehow as deserving of what happens to them. So eg God is seen as punishing someone. Discrimination is an action against people who may find themselves shunned, excluded. They/we experience homophobia rather than inclusion and welcome. Denial is prevalent and problematic: eg, AIDS is not serious, can be explained away, can be cured, isn't caused by HIV, can be dealt with by eating a balanced diet, doesn't exist, is the result of witchcraft.

### **Scripture: I have set you an example**

*“ Now that I, your Lord and Teacher, have washed your feet, you also should wash one another’s feet. I have set you an example that you should do as I have done for you.” Jn 13: 14-15)*

### **Scenario 2**

- The same group of care-givers visits a young woman of 25 who sits on a mat outside her home in the shade of a tree. She looks double her age because of illness, is very emaciated, and is unable to walk unaided. The care workers however get her to walk a few meters with their help. They have brought a parcel of clothes for her, some skirts and jumpers, and although she hasn’t much energy she is interested. She is given a bottle of juice, some of which she sips at once.
- The girl’s unemployed parents are present, and some of the discussion with them centers on what they could do to access a disability grant for her which would give the family some respite given that there appears to be no income. A decision is taken that the driver helping the care-givers move from home to home will take the parents to the relevant government departments on a particular day the following week; their affidavits, and their personal application, will hopefully speed up the process.
- The care workers take the young woman into the house where they and her mother wash her, massage her, and dress her in some of the newly acquired clothes, after which they help her to walk outside again. The care-givers ensure that the mother has sufficient disposable gloves to last her for some time as she takes care of her daughter.
- Everyone gather under the tree again, and the care-givers lead a prayer service. The mother is clearly moved by what is happening, and the young woman although not really able to participate is appreciative of all that is being done for her. Again I have a lingering question to do with whether the help being offered the young woman will be effective in the bigger picture of dire poverty.

### **Psychological/emotional care/support needed by carers**

- Acknowledgement of each person’s contribution to the team, to the work of the project, to the care of specific people.
- Recognition of effort and emotion expended given that there are not always measurable benefits to care-givers themselves.
- Support on an individual level, of each person, since each care worker comes with his or her own needs, related perhaps to family problems, distances to be traveled, own health concerns.
- Debriefing on a regular basis, with other care-givers, around the stresses of having to deal with a multiplicity of deaths, with conditions of poverty and deprivation, with perhaps being as poor as the people being helped.
- Counselling opportunities for individual care-givers.

- Support groups for care-givers, some of whom may themselves be HIV+ or living with AIDS.
- Incorporating cultural practices into how we show support to one another.
- Time-limited contracts with care-givers, which are renewable, but which also help to set boundaries.
- Adequate supervision/boundaries/parameters for care-givers who cannot reasonably be expected to organize themselves, visit the sick, monitor their own performance, and take care of their own debriefing.
- Clear “job” descriptions/expectations for care-givers are a must if there is not to be unhappiness on all sides when misunderstanding creeps in
- Appropriate goal-setting and challenges can help care-givers to grow both professionally and in their personal lives.

#### **Social/material/financial support: some ideas**

- Material resources made available for what is to be done
- Monetary/financial reimbursement
- Travel reimbursement
- Volunteer contract, renewable
- Uniforms, shoes, umbrellas, means of transport
- Assistance with medical aid, retirement policy, funeral policy
- Assistance with family needs/school fees
- Skills development/training

#### **Spiritual/pastoral support: some ideas**

- Retreat days
- Days of prayer
- Healing service
- Time out/away/off
- Prayer times/services
- Pastoral counseling
- Sacraments/sacrament of the sick
- Support of parish clergy, other parishioners, parish pastoral council

#### **Some thoughts about the Church and care-givers**

- Church/ parish ownership of programmes done in its name supports the care workers and the beneficiaries of care whether in formal settings such as hospitals and hospices, or in homes
- Recognition of the work of care in the Church’s evangelisation; the mission of Jesus is being continued when care workers reach out to their brothers and sisters in need.
- Care workers are pastoral agents. Care workers see themselves as doing the work of the Church.

- Some care workers see themselves doing the work the Church isn't doing.
- South Africa lost Church hospitals and clinics during the time of apartheid. We are seeing new forms of health care provided, in more informal kinds of settings, by care workers, many of them not professionally trained but providing an unbelievable response.

### **Some questions for which we need to find local answers**

- What training, supervisory and mentoring opportunities are being put in place to support care-givers?
- If care-giving is also somehow about pastoral care, how are care-givers being trained and supported in this? Care-givers themselves as members of parish communities need to be beneficiaries of pastoral care. What is happening in this regard?
- If care workers are being remunerated or compensated in any way, are the conditions around this clearly understood by all concerned? Are there job descriptions and contracts in place?
- Research has shown that volunteer commitments have a certain time span, after which people move on to something else, to a paying job, or whatever makes more sense at a particular time. Do we understand this sufficiently when we engage the services of care workers?