

SPIRITUAL PERSPECTIVES ON HIV – SCOTLAND AND BEYOND

Editorial note: In this article we hear from three chaplains who describe ongoing work in the field of HIV/AIDS. They describe ways in which those living with or affected by HIV/AIDS, and their communities, both in Scotland and the wider world, can be helped to face the emotional, physical, practical and spiritual challenges involved. Each contribution in its own way speaks about the re-creation of hope and fullness of living.

The Editors

3RD DAY PEOPLE

Marion Chatterley

Abstract: A diagnosis of HIV no longer implies a rapid progression to AIDS and to inevitable death. From the perspective of her work in Edinburgh, the author describes how the work of chaplaincy has changed in response. It now seeks to offer ongoing spiritual and pastoral support, in a variety of settings, to those living with HIV, and to their various communities within Scotland.

Keywords : HIV/AIDS; spiritual care; pastoral care; chaplaincy

An HIV diagnosis was (and in some places still is) understood as a diagnosis of rapid progression to AIDS and imminent death. For people living in Scotland, the situation has changed dramatically. Rather than facing a rapid journey to Gethsemane and the horrors of Good Friday, many people have found themselves moving through that situation and now find themselves living a resurrection experience. The spiritual challenges facing the population of people living with HIV in Scotland are different from those facing people who are living with HIV in other parts of the world, but are equally demanding.

The history:

The history of Chaplaincy services for people living with HIV mirrors the history of the development of the epidemic in the Scotland. In the very early days of the epidemic, the Bishop of Edinburgh appointed a Chaplain to the community of people living with and affected by HIV. At that time, an HIV diagnosis assumed a fairly rapid progression to AIDS and

inevitable death. The Chaplain's work became focussed on the needs of those who were dying and bereaved, developing along the model established by the Hospice movement when Milestone House, a purpose built hospice was opened in 1991 in Edinburgh.

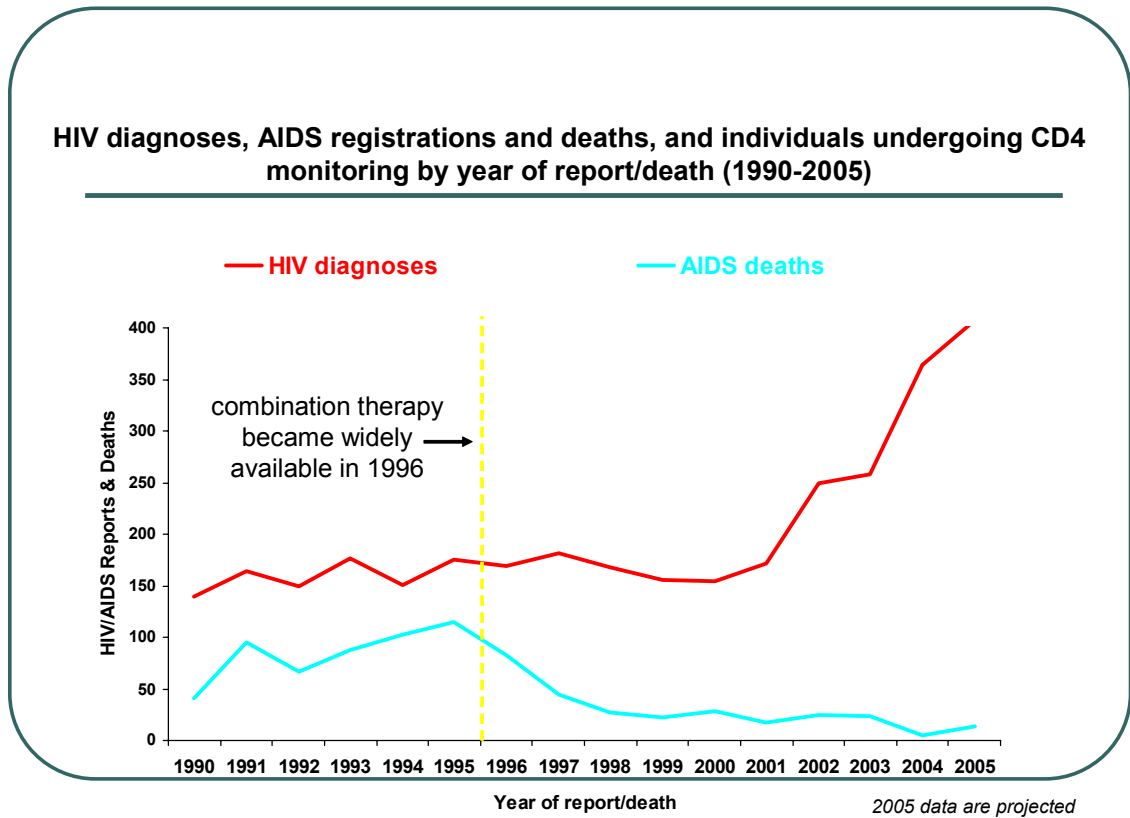
Edinburgh had a particular need for services as a very large number of intravenous drug users in the city had been infected with HIV in the early 1980's. This significant group of people presented with particular issues and care management problems. Many were still using illicit drugs and living chaotic and unpredictable lifestyles. Milestone House was able to develop appropriate services, both for this group and for the significant number of gay men who were diagnosed as HIV Positive.

Chaplaincy was a valued and integral part of the services offered within Milestone House by Waverley Care, the major provider, in Edinburgh, of sup-

port and care services. By 1996 Combination therapy was being developed and it soon became clear that the prognosis for people living with HIV might

not be as grim as had been anticipated. The effect on mortality was marked – as seen in table 1.

Table 1



A changing picture:

The changing picture for people living with HIV precipitated a review of support services, resulting in a significant change in the services offered by Waverley Care. The hospice service was closed and a new social respite model was developed. The requirement for the chaplaincy service was to look at ways in which spiritual and pastoral support could be offered within the new service model.

The decision was made that Chaplaincy should no longer be an institutionally focussed service but should develop along the lines of a parish ministry model, offering ongoing support and care to people

whether or not they were using the residential unit. In practice this means that the Chaplain might make an initial contact with people when they are in residential care and will then follow up with home visits and community based support. She will support people to make connections in a range of places of interest to them within their community. For example, visits to art galleries or coffee shops; support to visit places of worship – whether to participate in a service or simply to manage to go into the building. Service users have a mobile phone number for the Chaplain and know that they can call to access support in a crisis. There has been an increase in the

number of referrals from people who do not use the residential unit, but wish to access chaplaincy support. They meet the Chaplain at a mutually agreed location – whether the person's home, Waverley Care information centre premises or a café.

This development has been very interesting. It has allowed the nurturing of ongoing relationships with service users built only on a premise of unconditional love. Many of the regular users of Waverley Care's services are people with complex histories who are living with significant emotional damage. A Chaplain can offer a glimpse of God's love and so offer people a gateway into deep and lasting change.

A range of client groups:

Throughout the history of Chaplaincy with this client group, there has been a need for work with Lesbian, Gay, Bisexual and Transgendered (LGBT) people who have been damaged by faith communities. The experience of faith communities for many LGBT people has been at best negative, and at worst destructive. An ongoing element of the Chaplain's work has been to work with people to heal those abuses and to offer an alternative and positive understanding of God's love for all people regardless of their sexuality.

In the early years of this century, it became apparent that an increasing percentage of people testing positive for HIV were from Sub Saharan Africa. This group of people present a new set of challenges for services. Often their immigration status is uncertain – and the need to access HIV treatment is not accepted by the Home Office as a valid reason to remain in Britain. Africans tend to present late in their disease progression for testing and so have more complex treatment needs. (Burns et al 2001). In 2003, Waverley Care published a preliminary report into the needs of Africans in Scotland who are living with HIV (Sinyemu and Baillie 2003). One significant finding in relation to spiritual health is that 47% of those interviewed were affiliated to a religious body. In their follow up research (2005), Sinyemu and Baillie found that 24 out of 25 interviewees (96%) described themselves as Christian, compared with 65% of the Scottish population (Chief Statistician, 2005)

As a result of this research, and of informal conversation with African service users, it soon became

clear that there was a need to make links with the African led churches – which act both as worshipping communities and centres for emotional support. None of the African led churches in Scotland is affiliated to a mainstream British church, so there has been no obvious point of contact or shared reference point. However, progress has been made and a seminar for African church leaders is planned for late in 2006. Discussion with leaders within the African churches suggests that there is a role for the Waverley Care chaplain to support pastors in their role with members of their congregations who are living with/directly affected by HIV. Stigma and discrimination is a significant issue within the community and makes it more difficult for people to disclose their status within the church. Support from an external religious source might be one way to begin to address this issue.

Ministering to 3rd day people:

The current situation is that three distinct groups form the community to whom a Chaplain to people living with HIV must minister. These groups have little in common other than their HIV status and yet all have clear pastoral needs. For long term survivors of HIV (some service users have been living with the virus for more than 20 years) there are issues of survivor guilt, of managing multiple bereavements, of finding ways to live with HIV rather than waiting to die from AIDS. Women who were told they would be lucky to see their child starting school now find themselves childminding that child's own children. People whose partner died a few years ago are now daring to believe that they might live long enough to make another relationship worth trying. People are finding ways of adapting to living with the medication and the restrictions that chronic illness inevitably brings.

Africans in Scotland face particular problems. They have access to treatments here that would not be available at home – even if they were in a position to afford them. Many have no secure immigration status and live with daily fear and uncertainty. Couple that with the problems of living in an alien culture and finding your sense of cultural identity within a faith community which may be quite conservative in its outlook, and daily life becomes a daily challenge.

Infections rates for HIV have rocketed in the past 2 years. 406 new infections were reported in 2005 compared with an annual average during the 1990's of between 150 and 180. (Health Protection Scotland, 2006). The issues for any relatively young person who has been diagnosed with chronic illness and is forced to face their own mortality are real and intense. The issues for young people living with a sexually transmitted disease are even more complex. The negotiations that are necessary to ensure safe relationships are tricky for any of us; for a newly diagnosed young person they are especially taxing. It is not surprising to learn that the incidence of depression is higher than average within this population.

Supporting People as they journey towards their Resurrection experience:

The fundamental task for a Chaplain to people living with HIV is to journey with them as they move from a Good Friday perspective to and Easter Day vision. The basic spiritual care that is needed allows people to mourn the inevitable losses that come with an HIV diagnosis, but then to find ways to rejoice in

the opportunities that are ahead and to find ways to live a fulfilling and enriching life.

References

BURNS FM, FAKOYA AO, COPAS AJ, FRENCH PD (2001). Africans in London continue to present with advance HIV disease in the era of highly active antiretroviral therapy. *AIDS*, 15 (18): 2453-2455
CHIEF STATISTICIAN (2005) *Analysis of religion in the 2001 Census: Summary Report*, Office of the Chief Statistician February 2005 <http://www.scotland.gov.uk/stats/bulletins/00398-02.asp>
HEALTH PROTECTION SCOTLAND (2006) *Focus: HIV in Scotland review 2005*. Weekly Report Vol. 40. No. 2006/03
SIMYEMU, E and BAILLIE, M (2005) HIV becomes your name. A report on the issues facing Africans living in Scotland who are HIV positive. Waverley Care. www.waverleycare.org
SIMYEMU, E and BAILLIE, M (2003) African Report www.waverleycare.org

Marion Chatterley is a priest in the Scottish Episcopal Church, and a chaplain with Waverly Care.

'LIFE ON THE OCEAN WAVE!'

SPIRITUAL CARE, MENTAL DISTRESS AND HIV

Cameron Langlands

Abstract: The Tidal Model is a holistic approach to healthcare. It focuses on the personal journey, using the metaphor of a sea voyage. The journey may at times feature storms, breakdown, rehabilitation and recovery. This article describes how the model may be creatively used by chaplains and other members of the healthcare team working with those coping with mental distress and HIV.

Keywords : HIV; Tidal Model; spiritual care; chaplaincy; holistic care.

"We are committed to providing holistic healthcare that is responsive to the physical, psychological,

emotional and spiritual needs of our patients and staff." (NHS HDL 76 2002)

“People will forget what you do, people will forget what you say but they will never forget how you have made them feel.”

Craig is 35 years old. He was diagnosed as being HIV+ three years ago and was seemingly coping with all that the news encapsulated. Recently his mother died. He had nursed his mother for over five years at home, being her principal carer and felt he ‘had to be strong’. With her death, thoughts of his diagnosis and own mortality re-emerged and he found it hard to cope. Shortly after the funeral he was admitted to a psychiatric hospital with clinical depression.

Traditionally care for patients in situations similar to Craig’s, who had a dual diagnosis of a mental illness and being HIV+, was the same as that for all patients within the psychiatric setting: namely, care based around the medical model where the impetus for care was focused more on detection and treatment than on assessment and support. In this setting Chaplains were often viewed as the people to deal with the ‘personal issues’ whilst the medical/nursing staff dealt with the patients physical care with the two paths rarely crossing. The medical/nursing care being given was seen as of far greater value than that of the personal/spiritual care of the Chaplain.

This no longer necessarily needs to be the case, and in Gartnavel Royal Hospital we have moved from this traditionally focused method of care and implemented the Tidal Model (Barker, 2005). The Tidal Model represents a more holistic approach to healthcare, focusing, as it does, on the person and their personal journey, which is extremely valuable when caring for those who have a dual diagnosis of being HIV+ and having a mental illness.

Borrowing from chaos theory (Barker, 1996), the Tidal Model uses the metaphor of water and views each of our lives as a journey that takes place on an ocean. It emphasizes the fluidity of our human experience and highlights just how changeable, unpredictable and unstable our lives are. (Barker, 2001) Throughout our lives ‘the person experiences storms or even piracy (storms). At other times the ship of life may begin to take in water and the person may face the prospect of drowning or shipwreck (break-down). The person may need to be guided to a safe haven to undertake repairs, or to recover from the trauma (rehabilitation). Once the ship is made intact

or the person has regained the necessary sea-legs the ship may set sail again, aiming to put the person back on the life course (recovery).’

Chaplaincy sits well within this approach as it is person-centered. Although the Chaplain is not a trained mental health professional s/he can use the principles encapsulated in the Tidal Model to build a way of operating that is complimentary to the approach being taken by the medical/nursing team.

The Chaplain is well versed in listening to people’s stories and the Tidal Model builds on this foundation. The story told by the person is given precedence as this is where the experience of their illness, trauma or life changing event is located. In contrast to the approach adopted in counselling, the Chaplain, using this model of care, is not interested in unraveling the patient’s problems. Instead, s/he *‘aims to use the experience of the person’s journey and its associated meanings to chart the next step that needs to be taken on the person’s life path.’* (ibid).

To do this the Chaplain engages with the person in three areas which they inhabit. The **self** is where people feel their world of experience. People who are HIV+ and in mental distress often feel incredibly insecure. Therefore we need to do everything we can to make the person feel as secure as possible. By doing this the Chaplain creates a space where the person can feel safe, where they can be open, honest and candid. A place where healing can begin to take place. The **world** is where people hold the story of what has happened to them and how they have ended up in hospital. Through conversation and carefully worded questions the Chaplain can explore the person’s story, revealing hidden meanings and identify resources that the person has to enable them to take the next steps towards recovery. The **others** represent the various relationships that the person has or has had. This area highlights those who make up the person’s community and those who can offer support and help. By exploring these areas the Chaplain places the person and their narrative center stage and, in doing so, helps the person to identify what needs to happen now. This is important as it is the **now** where the emphasis is placed.

The value of this approach can be distilled into ten commitments which, if followed, will prove invaluable when following this model:

1. Value the person's voice – remember that the person's story is paramount so listen to what they have to say.
2. Respect their language – allow people to use their own language, reflect that when clarifying what the person is saying, inhabit their world.
3. Develop a genuine curiosity – show a genuine interest in what the person is saying when they are telling their story.
4. Become the apprentice – learn from the person you are helping. After all, the person is the expert/teacher and we are the apprentice/pupil.
5. Reveal personal wisdom – the person is the expert in their own story so don't make assumptions and don't make judgments.
6. Be transparent – both the person and the Chaplain.
7. Use the available toolkit – the person's story contains valuable information so listen to it. They will tell you what is and is not appropriate for them.
8. Be creatively curious – the person and the Chaplain need to work together to learn what needs to be done to help the person.
9. Give the gift of time – time is the midwife of change.
10. Know that change is constant – change is inevitable as nothing lasts forever.

If we are being honest there is nothing new in the above list. It has been produced in various forms over many years. However, in saying that, it still runs counter to the way many people are treated when they enter hospital. Within my own setting and with a particular group of patients it is a model

that has proved invaluable in meeting their needs. And it is a model of care where the medical/nursing team and the Chaplain can work together in a complimentary way for the benefit of the patient.

In many ways, therefore, the Tidal Model can be seen as a prerequisite for the delivery of optimal health care. Perhaps Pierre Teilhard de Chardin encapsulated the concept best when he said, "*You are not a human being in search of a spiritual experience. You are a spiritual being immersed in a human experience.*" (Sheem 2005)

References

- BARKER, P (1996) Chaos and the Way of Zen : Psychiatric Nursing and the Uncertainty Principle. In *Journal of Psychiatric and mental health Nursing* 3, 235-243
- BARKER, P (2001) Tidal Model: Developing a Person-Centred approach to Psychiatric and Mental health Nursing. In *Perspectives in Psychiatric Care*, July-September 2001
- BARKER, P and BUCHANNAN-BARKER, P (2005) *The Tidal Model: a guide for Mental Health Professionals*. Brunner-Routledge: London/New York
- NHS HDL 76 (2002) Spiritual Care in NHS Scotland: Guidelines on Chaplaincy and Spiritual Care in the NHS in Scotland. Scottish Executive Health Department, Edinburgh
- SHEEM, G (2005) Spirituality and Religion in Multiethnic Palliative Care. In *Cancer Nursing Practice*. Vol 4, 1, p. 17-21

Cameron Langlands is head of the department of pastoral and spiritual care, Gartnavel Royal hospital, Glasgow

SACRED STARFISH

THE CHURCH OF SCOTLAND'S HIV/AIDS PROJECT:

MAKING A (REAL) DIFFERENCE

John McMahon

Abstract: The Church of Scotland's HIV/AIDS Project is concerned with practical, person centred care of those affected by HIV/AIDS in many parts of the world. It aims to offer solidarity and practical support, through partnership with those at the grassroots. The author describes his recent experience as part of a Partners' Consultation Conference held in Limuru, Kenya.

Keywords : Church of Scotland HIV/AIDS Project; (COSHAP); partners' consultation conference, Limuru; spiritual needs.

Ever the disgruntled 'liberal' and cynic of a cleric that I am (!), I never thought that I would find myself writing an article – and so happily, too – praising the work of the Church of Scotland! But that is what I am doing, and I am glad to be in a position to be able to do so. The Church of Scotland's HIV/AIDS Project (COSHAP) is just over four years old. Despite its youth, it has helped to enable remarkable work in HIV and AIDS, by supporting partners in small projects from around the world. Person-centred care of individuals and real, practical, grassroots help are simple ways in which faith-based organisations can offer authentic hope to people (and, therefore, communities) who live, on a daily basis, with HIV and AIDS.

Since its establishment, four years ago, COSHAP has realised just under half a million pounds (£0.5 million) to be spent in supported project work, generously gifted mostly by members of the church. At this year's General Assembly, the life of the Project (initially intended to be a five year enterprise) was extended to 2010, recognising the evidence-based success of recent partnership endeavours and, also, the church's desire to build capacity in areas where good and vital work is already happening. As Nigel Pounce, the Project Co-ordinator, points out, *with 10 people infected with HIV and six dying of AIDS every minute, every day, the need is obvious.*

The Project's aims are clear. People living with HIV, both in Scotland and around the world, do not look for sympathy but, rather, for solidarity and practical support. The Project helps to provide this through its partnership with others and in its commitment to:

- break the silence on HIV and AIDS;
- stand together with partner churches and faith groups;
- offer practical support;
- speak up for the voiceless;
- involve every member of the Church.

In January, of this year, I was extremely grateful and privileged, as a member of COSHAP, to be part of a Partners' Consultation Conference held in Limuru, Kenya. One representative from every project supported, around the world, was invited to join a capacity-building exercise, generously funded by the Scottish Executive. 32 delegates of 17 nationalities, working in 15 countries, representing supported projects and COSHAP itself, met to hear about each other's work, to share experiences and knowledge, and to grasp a common vision. And what an experience that was!

COSHAP supports a range of education, prevention and care programmes (in Bangladesh, Egypt, India, Israel/Palestine, Kenya, Malawi, Nepal, Nigeria,

Pakistan, Scotland, South Africa, Sri Lanka, Sudan, Thailand, Zambia and Zimbabwe). It would be impractical for me to write about all these wonderful projects in this article – so please do check us out online! – but just to give a flavour of some of the work supported, let me give some examples from just 5 countries.

In **MALAWI**, we help to support 3 different projects. The following extract from the Ekwendeni Hospital AIDS Programme report, just one project, perhaps best highlights the practical, grassroots nature of HIV work in this part of Africa, where issues of poverty are as life-threatening as disease:

“The AIDS programme is running the income generating activity (IGA) through community Volunteers and Village headmen. The main IGA is rearing of Pigs and Chickens. At the moment there are 79 Pigs. The programme has however slaughtered pigs for sale and for meat for Orphans and patients. The sales money was used to pay for 17 secondary school children in community day schools. The pig shelters are still increasing and the target of having Pigs in all the areas still remain. 470 Chickens were reared of which 70 were given to patient to eat and 400 were sold to pay school fees for 2 technical students.” (CofS, 2006).

In **NIGERIA**, we help to finance home-based care, provided for by the Care and Support Project of AIDS Action (a project of the Presbyterian Church in Aba). The money sent from Scotland helps to pay for 4 co-ordinators who meet with groups on a monthly basis, as well as support individuals day-to-day; they also make new contacts with people living with HIV and AIDS. Again, the following extract from their report demonstrates the basic nature of the care that is often needed:

“August 2, 2005. A meeting was held with people living with HIV (PLWHA) in the Presby-Aids Resource Centre Aba Abia State. The meeting started at 12:05 pm with an opening prayer by Henry O.C. Actually, there was no formal meeting because the time was used for focused group discussion among PLWHA in Aba, Abia State. The discussion group was comprised of the moderator, recorder, observer and participants (PLWHA). The first phase lasted for two hours with 10 PLWHA, after which the second set of participants, were interviewed. 23 PLWHA attended the meeting. Each PLWHA that

attended the meeting was given N500.00 for transportation, 30 capsules of Updyn, 30 capsules of Chemiron, 30 capsules of Cod liver oil and 6 tablets of Wormrax. Lunch was served.” (Ibid.)

In **INDIA**, 9 projects are supported in total, ranging from basic home-based care in the community (ie, in the slums), through awareness-raising and peer education with ordinary workers and youth, to higher education in theological seminaries (equipping theological students with the knowledge and skills to become practical, realistic pastors). One of the projects, HEADS (Health Education and Development Society), in Karur, works with slum youth to educate on sexually transmitted diseases and promotes safer-sex practice and good condom use. It also provides effective counselling services for those who test positive with HIV and, when necessary, ensures reliable home care and support for people living with the virus. The effectiveness and vital nature of this work relies heavily upon the network of support established which, in itself, has become a power with which to challenge the, often widespread, stigma and discrimination.

Countries like Scotland and Palestine/Israel, of course, have different needs and face different challenges. They are both countries with a low prevalence of HIV infection (compared, for example, to sub-Saharan Africa and Asia) and yet each, in their own way, encounter their own problems and peculiarities.

In **SCOTLAND**, for instance, a country materially and medically rich, we have worked with 6 different projects. One of them is Positive Voice, an Edinburgh-based support organisation for people living with HIV. From 2003 to 2005, COSHAP supported the production of Positive Voice’s newsletter, as well as enabling some advocacy work; and, at present, we help to provide a range of complementary therapies. Fiona, convenor of Positive Voice, was a delegate at the conference in Kenya and made the following, very interesting, comment:

“We have to find a way of inspiring people to get involved. We take so much for granted. We have tackled a lot of the physical stuff (with medication) but seem to have forgotten about the emotional and spiritual needs we all have. To some extent we are losing or have lost the sense of community that was so visible in the projects that people represented in

Africa. I believe we can always achieve more as a group than we can as individuals." (Ibid.)

In **PALESTINE/ISRAEL**, Mohammad Khatib, a Muslim, who also attended the conference in Kenya, works for The Galilee Society, a professional non-governmental organisation working for the health rights of Arab people (Christians and Muslims). The cultural and religious context of the Middle East makes it difficult for the issues of sexual education and health to be talked about openly and, therefore, stigma and discrimination are real threats. Nonetheless, The Galilee Society works hard to raise awareness both in the local context and, also, in the national media and it is especially encouraging to learn that a booklet, written in Arabic, was published for World AIDS Day, 2005, containing general information about sexual health and HIV and AIDS.

These projects are just some examples of the practical support offered. The Church of Scotland, of course (and it goes without saying), is not the only church or faith-based organisation involved in this kind of work. Other churches and faith (and non-faith) groups are involved, too. I will never forget, however, my experience in Kenya: leaving the largest slum in Africa (on the edge of Nairobi), with Mohammad from Palestine, a Muslim, who, with tears in his eyes, described the work of the church as "holy". For me, it was "human".

Many people will have heard a version of the story below, with which I would like to close:

Thousands of starfish are washed ashore. A little girl began throwing them back into the ocean so that they wouldn't die in the scorching sunshine. "I wouldn't bother, dear," her mother said, "It won't make a difference. There are too many to save." The girl stopped for a moment and looked at the starfish in her hand. She threw it back into the ocean, turned to her mother and said, "Well, it made all the difference to that one."

The Church of Scotland HIV/AIDS Project and our partners, at home and abroad, may not be performing miracles, but we are helping to make a real difference in the lives of people – and that's miraculous enough for me.

References

CofS (2005) *Good News: A Report to the 2005 General Assembly from the Church of Scotland HIV/AIDS Project Group*. Edinburgh, Church of Scotland.

CofS (2006) *On From Limuru: A Report to the 2006 General Assembly from the Church of Scotland HIV/AIDS Project Group*. Edinburgh, Church of Scotland. The Church of Scotland Online (<http://www.churchofscotland.org.uk/appeals/hivaid/index.htm>)

THE SCOTTISH EXECUTIVE
<http://www.scotland.gov.uk/News/News-Extras/intdevfundnov2005>

John McMahon is the Lead Chaplain for NHS Lothian Primary Care and Mental Health