

World Aids Day 2008

A contribution by Kathleen Marshall, Scotland's Commissioner for Children and Young People to the World Aids Day event organised by Waverley Care at Edinburgh, 1 December 2008

“Celebrate, reflect, remember. “ It seems fitting that this event takes place in a church. Even for those who have no religious affiliation or belief, churches stand as markers of significant times of life; births, marriages and deaths; coming to being, joining together in joy, and separation, and the rupturing of relationships, leaving behind someone who may now feel only half a person. The initial rawness of the loss gradually gives way to a more reflective remembrance, often bitter-sweet, that allows us truly to celebrate the meaning of a person's life and the richness of our relationships. And especially when someone has died after a long period of illness, the passage of time allows us to put those last days into a broader perspective; the demands of caring for some loved person whose needs may at times have threatened to overwhelm us; the guilt we may have felt at recognising the very real need to protect ourselves a little – to have a bit of time – a bit of respite to give us the strength to continue to care. Looking back, reflecting, we can see it all a bit better; how much we cared; how much we asked of ourselves; and how much we did. That is something to celebrate. Something to reflect on. Something to remember.

For those who are themselves living with HIV, Christmas time is also significant, whatever your religious belief. It marks the end of another year; an important marker for those whose illness makes them more aware of their mortality than those who travel blindly through the years, not thinking much upon it. It is a time for family and friends, for comings together with the aspiration towards that happy togetherness we see in the films and adverts, whatever the reality, whatever the stresses of living out the intensity of that closeness. We want it to feel different, magical, comforting, “holy” in the sense of being something a little bit apart; something different that transcends the ordinary calendar, the usual ways of marking time. We forget whether it is Monday, Tuesday or Thursday; the days have different names and different meanings. We are taken out of our ordinary world and its markers. We can flash back to Christmases past; the people, the places, the happenings, mundane or great that coloured this snapshot history of our lives; and we may also look forward, sometimes with anticipation, sometimes with fear and apprehension, hopefully with hope, and hopefully with an expectation of love.

Christmas also has an edge to it. It takes place at the darkest time of the year – harking back to ancient festivals designed to strike a blow against the darkness of midwinter – to light a candle in the dark – to proclaim hope in the new flourishing that will follow on as life reasserts itself. Life is only sleeping under the cold earth. We are confident that it will flower again.

Today is World AIDS Day; a celebration as universal as Christmas – maybe even more so in these secular days. And it is important that we acknowledge it as a celebration, even though what it builds upon is a devastating illness that has inflicted pain and misery on millions across the globe, including the children of affected parents, who may suffer a double blow; the loss of their parents and, for some – thankfully far fewer than in previous years - the burden of the infection itself which threatens their own future and their own identity. Identity is built upon the family links that we may have lost, our current view of ourselves and how we believe others see us, and our hopes for the future. The danger is that children and young people who are living with HIV have their identity shaped by the virus. Even with the medical advances that increasingly prolong life expectancy, the fact that people even talk about it to you when you are just entering adulthood must feel like a gross and unfair intrusion upon legitimate expectations that this is just the beginning of a long life adventure. The need for secrecy felt by some of those living with HIV can also be a barrier to intimate relationships, whether those at exist at the level of friendship or those that have the potential to go further.

For those who come to this country seeking refuge from war, persecution or deprivation in their home territories, there is the added loss – of culture, of familiar surroundings, of belonging, that can add to this feeling of loss of identity. This is where human rights, including the rights of children, are critical, because they are about human dignity, the dignity that everyone is entitled to expect, irrespective of age, race, culture, disability, HIV or immigration status. We truly are one global family. The mobility that can bring people quickly to our shores from far distant lands, the shared threats of a virus such as HIV and the victory of advances against it – that also need to be shared with our neighbours - bring home to us as never before how indivisible the human family is.

I did at one time undertake a lot of work on the rights of children affected by HIV and witnessed a remarkable progress in ways of preventing transmission and lengthening life. When I was preparing for this event, I looked back at some of the issues I had addressed. A lot of it focused on children affected in the womb or during birth. I looked at a booklet I co-authored in 1995, “Children’s Rights and HIV: A handbook for working with children and their parents.” There were lots of issues around telling children of their HIV status, especially when doing so disclosed confidential information about their parent; lots of issues about who needed to know and who didn’t; and dilemmas – for example, how you balanced the need to:

- let children know at an appropriate time about their own HIV status or that of their parents or siblings;
- support them to maintain their self esteem in a world that often misunderstood the infection and methods of transmission, and stigmatised and marginalised those affected by the virus; but at the same time
- teach them to be discriminating about who they told about their own status or that of others in their family.

I have looked at some of the more recent information about HIV, and it looks as if some of those issues have moved on as there seem to be fewer mother to child transmissions, but the babies of that era are now entering adolescence or adulthood – a great blessing in itself, but a situation that presents other challenges. Young people need to be able to live in celebration of their bright, shining present moment, with faith in themselves and those around them, hope for the future and an expectation of love from a world that seems to have gone frighteningly cold on the issue.

Living the present faithfully, hopefully and lovingly is our best possible contribution to the future, and the validation of *our* past and all those we have known, whether they are still with us or not.

Asserting our *own* human dignity and worth in the face of ignorance and prejudice is not an indulgence, but a gift all of us can bring to a world that needs to *know* better – needs to *do* better – needs to *love* better.

This time of year is about challenging the darkness with joy, light and togetherness. It is a time for:

- *Celebrating* the people we are, in spite of all the hard times, and celebrating the people we know who love and support us;
- *Remembering* the people we have known who still live with us through love; and
- *Reflecting* on how we bring the HIV secrets and the people who carry them into the light where they can flourish and grow – where those infected or affected by HIV can *be* the best they can be and spread their *own* light on others; light that has been fuelled by the strength and intensity of their own experiences; light that is a *gift* to a world that needs to receive it