

On Sunday the 18th of May a 25th Annual Candle Light Memorial event was held at the National Museum of Australia. The theme for this year was *“Never Give Up, Never forget”*. The following is a speech given by Stephanie Buckle

Another cold Sunday night in May, another Candlelight Memorial, and once again we've come together, because we want to remember people who died from HIV/AIDS, people who have lost someone to the illness, and people who continue to live with it and struggle with it. As on other days of mourning and remembrance, we want to make a testament to the lives of those who have died, to honour them in our thoughts. And we want to do this together because we've shared elements of the battle together. Here we know that we're with others who understand what it is to lose a partner, a son, a brother, a sister, a workmate, an entire generation of friends; to watch a whole community decimated by a disease.

When we say their names, we'll remember their courage, and their youth; we'll remember how they laughed with us, what they showed us, what they gave us. We'll say to ourselves again: we will always keep them with us.

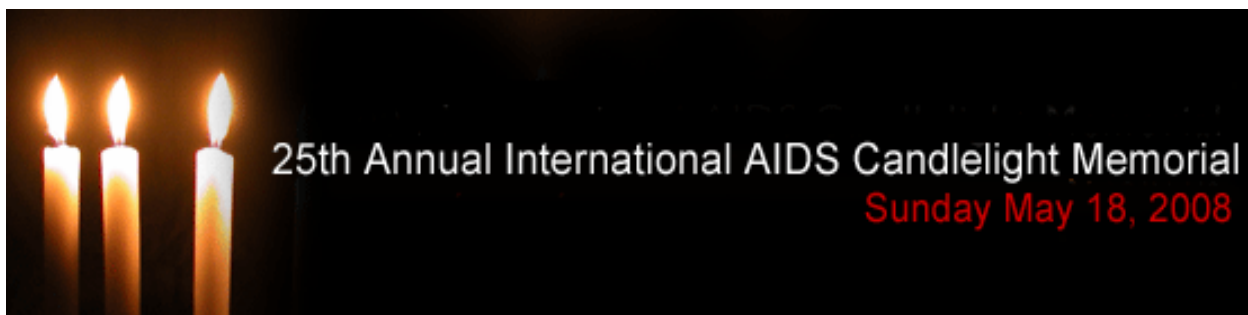
We can be thankful that things are so much better now. From our first tentative and very qualified use of the term “chronic manageable condition” some time ago, we have gained some confidence, to look around with a degree of pride and relief, and count the things that have been achieved – treatments, while imperfect and sometimes difficult to take, at least exist; the numbers of people dying

have dropped dramatically; services are well funded; there is a choice of doctors; many people with HIV want to just get on with their lives, and are able to do that.

But many of us here tonight remember how hard won these things have been. We remember the added, inexcusable burden that discrimination placed on sick people and their families – the body bags and the funeral directors who refused to open them, the hospital caterers who left trays at people's doors, and the politicians who suggested quarantine was an option. We remember the mystery illnesses that no one had seen or knew how to treat; the terrifying suddenness with which a vital young person could get sick and die. We remember AZT – the one treatment option, and how we clung to it, this leaky raft, in the hope that something better would come along. For many people, triple combination therapy was too far away.

Tonight, I want to acknowledge not only those who have died, but all of the people who stayed with them through the battle, partners, families and friends, all of the thousands of people who we say are affected by HIV rather than infected, as well as health care workers, educators and researchers who made their own essential contributions.

Mothers, fathers, partners, and other



family members lived every day with uncertainty, their own lives often taken over by the sudden and dramatic twists and turns in the progression of the illness. Being a mother myself, I particularly identified with the many mothers I met over the years, nursing their child at home, or in the company of strangers, trying to remain cheerful and positive, because that was the most helpful thing, doing one thousand and one practical things to help on top of what they usually did (running a business, or looking after the rest of the family), and that hardest thing of all – just being there, holding on to hope while they were essentially helpless. They saw their sons – and daughters – die.

Perhaps one shouldn't speak of a silver lining in this terrible time, but some good did come of it, and I want to remember that too. In fighting for the rights of HIV positive people, a community came together as never before. People became volunteers, they joined twenty four hour care teams, they took positive people shopping and to medical appointments. Others offered their professional services for free, or they lobbied for the establishment of services where there weren't any. Doctors took on massive workloads and risked their careers. People sat on Boards – for hours at a time, grappling with policy formation, supporting salaried staff. People formed alliances that had never been thought of before – sex workers, doctors, people with haemophilia, and bureaucrats all sat down at the same tables.

The GLBTI community outed itself in this fight – it was as if people said, “This is my family! This is my fight! This affects me!”

In the last six years, there have been steady increases in infection rates again. After a decline in new infections through the nineties, from the year 2000 the rate has again been climbing, particularly in Victoria and Queensland.

The GLBTI Health Alliance has called for leadership from the Commonwealth Government and a renewed commitment to improving the sexual health of all GLBTI Australians. They are asking for a review of the National HIV and STI Strategies, and a streamlining of the approval process for Commonwealth funded HIV programs. On the local level, much has still to be achieved; we cannot afford to rest on the achievements of the past. Many HIV positive people are struggling with poverty, and discrimination still lurks. Twenty years ago, the death of a gay man whose long-term partner had nursed him through his illness, left the partner without access to his superannuation. Today, very little has changed. While we may be no longer needed on care teams, there are still many battles to be fought. Fighting them together makes our community stronger.

Stephanie Buckle
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