

"... and one dare to hope and dare to remember".

Memory Work: Coping Strategies in the Face of AIDS

Conference of aidsfocus.ch, Swiss platform HIV/AIDS and International Cooperation

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## **"... and one can dare to hope and dare to remember"**

How children and adults living with AIDS can gain new courage  
through memory work

Report from aidsfocus.ch conference

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The aidsfocus meeting held on 12 April 2005 in Berne was entitled "... and one can dare to hope and dare to remember. Memory Work: Coping Strategies in the Face of AIDS". It brought together over 60 participants, mostly representatives of Swiss aid organizations and the Swiss Agency for Development and Cooperation, and guests from other countries. All took full advantage of this forum for information and experience sharing and for learning together to provide lively and stimulating input and to pursue extensive discussions. The focus of the conference was the opportunities offered by and the limitations of memory work as a way of providing psychosocial support for people living with HIV/AIDS. Presentations by international experts in the field and working groups were given an added dimension by a special memory book made for each participant from cardboard and decorated by the sheltered workshop in Zurich; the purpose of these books was to enable each participant to take an individual approach to the subject of the conference. As one person put it: "My own memory book helped me to "own" the project and not see it as something from the others or about the others."

The conference picked up the theme of the "**flower**" which formed the close of last year's aidsfocus.ch conference on comprehensive treatment and care. The flower symbolizes a "comprehensive care package" for people living with HIV/AIDS, comprising psychosocial care, medical treatment, clinical care, home-based care, financial support, countering the stigma of HIV/AIDS and support for human rights, information and prevention. These are all elements of a comprehensive approach to stemming the continuing spread of HIV/AIDS and solidarity with those affected; and they are all elements which complement and reinforce each other.

A good example of this holistic approach is **NACWOLA**, the National Community of Women living with AIDS in Uganda. NACWOLA attracted international attention with its "memory books" in which mothers with AIDS tell their children about the important things in life and try to give them a feeling of belonging. **Annet Biryetega**, NACWOLA's national coordinator, talked very vividly about how memory books improve communication between HIV-positive parents and their children. Working on a memory book makes it easier for parents to explain their health status and other important, difficult things to their families step by step. The focal point of the project is the many children who have lost their parents to AIDS. The psychosocial support they receive from NACWOLA has given them new courage to live. Writing a memory book is always an integral part of a larger care package which includes, in particular, the promotion of social skills, psychosocial counselling, the organization of children's clubs, vocational training for children and activities that generate income. Annet Biryetega read out some truly moving testimonials from children in the project. B., a 16-year-old orphan, described his experience as follows: "*My parents died of AIDS I was 10 years old. I*

*became a destitute after the death of my parents because life had lost meaning, my 2 little brothers went to live with a distant relative. My life changed when I met NACWOLA women sensitizing in the community... They asked me to join the children's club for counselling, consequently I benefited from the training of the memory project. My life has changed so much. I now live in our home, I brought my little brothers back and now I am the head of the family. I have been trained in skills of carpentry so I make stools and tables to sell, I earn income from car washing. My little brothers are in school and they are happy, NACWOLA mothers often visit us."*

Memory work can take a number of very different forms and is constantly being enhanced and refined in the practical setting together with adults and children living with AIDS. "Strength from Remembering", the film produced by aidsfocus.ch and realized by René Schraner and Eva Hänger, is a moving documentary of three methods used in memory work and how they are implemented: memory boxes, memory books and body maps. **Jonathan Morgan**, one of the protagonists in the film and former Director of the memory box project at the University of Cape Town, plays a central role in developing and propagating memory work in southern Africa. He defines memory work as "the deliberate setting up of a **safe space** in which to **contain** the telling of a story as a key element of memory work". The vital element is the space that allows adults and children to express their feelings, experiences, doubts and hopes in words and pictures. They develop a new perspective on life through telling the story of their own life, sharing it with others and sharing others' stories as well.

Jonathan Morgan worked closely with people undergoing medical treatment and the doctors treating them to develop the Tracing Book. This handy book contains outlines of the human body, and patients can use it to illustrate the physical and emotional changes that they go through during treatment. The book makes it easier for many patients to communicate with the doctor, nurses or their counsellor, and it also helps them to take their medication regularly, an aspect of enormous importance.

Another impressive example of memory work is the **Hero Book**. It is a document and process in which children are invited to become the author, illustrator, central character and publisher of a book. In a shared process children recount and draw events and challenges from their lives and the feelings that they trigger, both good and bad. This helps them to realize their own strengths and to see what "heroic acts" they have done. It is a guided process which helps children to process traumatic experiences, to understand their self-worth, to build self-confidence and to draw new strength.

Jonathan Morgan believes that Hero Books are an important tool in the **scaling up** of memory work as part of the Ten Million Memory Project (10MMP). This ambitious undertaking is guided by the vision of providing psychosocial support in the form of memory work for 10 million children in Africa by the year 2010. The driving force behind the project is the regional network REPSSI (**Regional Psychosocial Support Initiative For Children Affected by HIV/AIDS**). **Noreen Huni**, regional Director of REPSSI in Zimbabwe, reported on how REPSSI has been working with legal advisers and partners to develop new methods and to introduce them to a large number of organizations. In its role as a networker and catalyst, REPSSI has mobilized a large number of separate local initiatives, enabling them to mature and provide mutual support. This has provided a massive boost to efforts to scale up comprehensive responses to support children affected by AIDS in Africa.

"Memory work is a first-aid kit," was how Noreen Huni described the importance of this work. Psychosocial care and support are more comprehensive and go beyond this level: "Psychosocial care and support are interventions and methods that enhance children's, families' and communities' ability to cope, in their own context, and to achieve personal and social well-being; enabling children to experience love, protection and support that allow them to have a sense of self-worth and belonging." Interventions and methods of this type are vital in enabling children to develop healthily in these traumatic situations

and to have faith in the future. The core elements of support for children affected by HIV/AIDS include bereavement work, spiritual support, reduction of the risks caused by HIV/AIDS and vulnerability, stress management and peer support as a preventive strategy.

## **Discussions**

The plenary sessions only touched on the importance of psychosocial support for people being **treated with antiretroviral drugs**. The working group on treatment and memory work attracted the largest number of participants. Guy-Bertrand Tengpe, a psychologist who provides counselling and support for patients being treated with ARV drugs under the programme run by Médecins Sans Frontières in Cameroon, talked about the “Lazarus syndrome”: people who are diagnosed as being HIV-positive often perceive this as a death sentence and subsequently experience the results of treatment with antiretroviral drugs as rebirth. Many people who have already resigned themselves to dying and are then “brought back to life” have difficulty in coping with this situation. Psychological counselling which takes the patient back to life before the disease creates a new desire to live in these people, and encourages them to adhere to the medication. The participants in this working group were convinced of the necessity of psychosocial support for patients undergoing drug therapy, and of the role that memory work can play in this context. The organizations at the meeting which provide ARV therapy – Médecins Sans Frontières, the Swiss Red Cross, Swiss AIDS Care International and Solidarmed – are now determined to add psychosocial care and counselling to their programmes, and to this end are looking for alliances with partner organizations of aidsfocus.ch in Switzerland and locally. The purpose of these alliances is to enable each organization to contribute its special knowledge and skills. They would also like aidsfocus.ch to produce a detailed, country-specific overview of “who does what and where”.

While it is important for people to realize and accept the fact that medical treatment and care and psychosocial support are mutually beneficial and mutually dependent, we must not forget the message of last year’s conference and its call for universal access to comprehensive treatment and care. As mentioned before, and as reiterated in the working group and the plenary sessions, treatment, care, psychosocial support and prevention are all part of a holistic approach that is vital in the battle to stop the spread of HIV/AIDS. This is a battle in which every organization has a part to play.

## **How can memory work be promoted and implemented in individual projects?**

Below are some of the suggestions discussed in the working groups and informally:

Memory work is for everyone, but not everyone can or should integrate memory work into their projects. Memory books can improve communication and relationships between parents and children, as numerous examples have demonstrated very clearly. But Memory work such as unconsidered, premature information given to children about their parents’ status, for example, can destroy relationships. In the worst-case scenario it can traumatize the children and drive them to suicide. Great caution and good therapeutic guidance are particularly vital when patients draw their own body maps. These are very personal and direct and can re-open old wounds. They must only be used in an atmosphere of trust and confidence.

Memory work as a method is accessible to and can be explained to anyone with an interest, and training manuals are published on the Internet. However, it must not be forgotten that psychosocial work with traumatized children and adolescents requires special training. In the words of Noreen Huni, memory work is a useful “first-aid kit” for “minor wounds”, and where necessary it must be integrated into and supported by additional measures.

For these reasons it is necessary for project staff who intends to use memory work to receive the proper training. REPSSI, the Zimbabwe Red Cross and NACWOLA have carried out training courses for memory work facilitators, and information on further courses is available on request.

### **What next?**

The conference provided a platform for presenting current knowledge, expertise and experience with memory work and psychosocial support, for publicizing it, sharing it, and developing it further – in short, a space to share. aidsfocus.ch was able to benefit from the experience and knowledge of guests from the southern hemisphere, and they in turn found the discussions at the meeting extremely useful. The conference set in motion thoughts about the importance of memory work and psychosocial support in the context of a comprehensive strategy, and also motivated many people to implement it. It also provided space for networking with others interested in specific topics and thus created a basis for a future exchange of information and potentially also collaboration in an operational context.

Following the conference, the intention is for participants to pursue advocacy and lobby work within their own organizations in support of the integration of psychosocial care and memory work. A majority of the participants made a written personal commitment to disseminate information within their organization, to motivate programme coordinators and/or decision-makers, and to promote the introduction of memory work into their organization's projects in Africa, Asia or eastern Europe.

Information on training opportunities and handbooks containing contact addresses can be found on the Internet at [www.aidsfocus.ch](http://www.aidsfocus.ch). aidsfocus.ch will also be issuing a toolkit for memory work containing examples of memory books, the film "Strength from Remembering", contact addresses and links. A short list of organizations and projects focusing on treatment and care, and/or on psychosocial support will be drawn up and published.

The concrete implementation and integration of HIV/AIDS, including psychosocial support and memory work, into existing projects and programmes (mainstreaming) is still a major challenge for specialists working in development cooperation. The intention is to identify options for an exchange of opinions and experiences and for joint learning within aidsfocus.ch so that appropriate events can be organized.

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