Information on the Memory Project

1. PLANNING FOR OUR CHILDREN'S FUTURE

Aids has affected so many parents and people of working age, leaving many extended families swamped with responsibility and unable to take in any more dependant children. In other cases families have been torn apart by fears and mis-beliefs to do with Aids. So, in too many cases, the traditional systems of care by relatives or clan members, or informal arrangements with neighbours or community members, can no longer to be relied on.

Although there are now effective treatments for people with HIV/Aids, it is likely to be many years before they (ARVs) become universally available and in the meantime, the terrible reality is that many more children will be orphaned, joining the millions who are already struggling to survive without parental guidance and without a secure plan for their future. Therefore in the Memory Project training programme great emphasis has been put on helping parents to look their worst fears in the face and start really thinking about different ways their children could be looked after in the event of their early death.

Over the past fifteen years groups of parents have tried out the ideas described below. However ill and desperate they felt, they showed that they wanted to do their best for their children – but they needed help to work out what would happen if they died before the children were old enough to look after themselves. The structure of the Memory Book together with practical workshops on opening up communications with children, planning ahead and making the future as secure as possible, empowered many of them to overcome their fears about disclosing their HIV status. Being open within the family knocked the first hole through the wall of silence and once they were free of the terrible burden of secrecy they found they had more energy and confidence to face the future. Many parents were also surprised to find out how well their children coped with the facts and that they welcomed the opportunity to be involved in working out the best solutions for the family.

The Memory Project training programme which is summarised below (and available on this website) is built upon the experience and inspiration of these pioneering parents. However, though there are frequent references to families living with HIV/Aids, we believe that much of the information, and suggestions for practical things to do to protect children, would apply just as well for the huge number of families whose lives are overtaken by disasters beyond their control and where children risk being separated from their parents, for example by war, famine or migration.

With or without Aids as a factor in the immediate family, many children are surrounded with uncertainty and risk. If parents can open up communications in the family, provide their children with a strong sense of identity and help them prepare for the unpredictable future, this will go some way to help them survive whatever problems come there way.

> ***So, as much as we may hope that the HIV crisis is past its peak, and that other disasters are better controlled, we believe that this is not the right time to cool down on the ideas suggested below. On the contrary it is time to rev up efforts to help parents to prepare and plan for their children and to spread the ideas as far and wide as possible.***

These ideas started with the Memory Book* which made it easy for parents to put together all the information that children need to know about who they are and how they fit into their wider family and community. When parents started to write their Memory Books they realised there was a lot more they needed to do to give their children the best chance to survive tough times in the future.

These were some of the questions they asked:

- How can we start talking with our children, telling them important (and often difficult) information and listening to what they have to say?
- If we have HIV or face other serious problems in our family, HOW can we begin to make plans that will keep our children safe in the future?
- If we manage to make plans, how can we be sure they will happen ?
- What can we do to prepare our children for the possibility of our death and that their lives may completely change?
- If we are not there to bring them up how can we help our children to hold on to their sense of identity, to know who they are and where they belong?

These and many other questions were gradually built into a training programme which became known as **The Memory Project.**** The **Memory Book** and the contents of the **Memory Project training programme** have now been made freely available on the **Memory Project Website***** for anyone who wants to use them.

A summary of the main topics covered by the Memory Project is given below. (These and other relevant subjects are covered in much more detail in ten Training Topics, all of which are or will be available on the website.)

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2. PUTTING CHILDREN IN THE PICTURE AND INCLUDING THEM IN MAKING PLANS FOR THEIR OWN FUTURE.

This involves helping children to understand what is going to happen in the future and who they can trust for support and advice. It means using the time that is left to pass on knowledge and skills so children will be better prepared to cope on their own in the future.

A huge problem for parents living with HIV/Aids is when and how to start talking openly to their children about their sero-status. The later they leave it the more frightening it becomes. Meanwhile children, who have often guessed the truth, are left with their questions unanswered and their fears about the future getting worse day by day. (Although this paper mainly refers to the problem of HIV, keeping quiet about other "secrets in the family" can be just as damaging – even very young children pick up the signals when something is wrong.)

If they don't learn the facts until after the death of their parent, children often react with anger because they were not trusted with the truth. They have also been given an unspoken message that Aids is unmentionable. This increases their sense of stigma and isolation.

They will have to cope alone with their grief, their shock and their fears about Aids at a time when their lives are being turned upside down. This might include being separated from brothers and sisters or being moved to live with virtual strangers. Worst of all, it's too late to get answers directly from their parents. That chance has been lost forever.

Parents need to understand that knowing the truth about Aids is generally less terrifying than being left in the dark to worry alone. On the contrary, when children are allowed to share the family problems they are already starting to face up to their future loss; they understand why they are being asked to take on more of the household duties; they can use every opportunity to pick up skills and knowledge from their parents; they can learn first hand about HIV transmission and how to stay safe (and what better form of protection can there be than hearing about it from your parent who is living with the reality?)

If their parents give them a chance to speak for themselves children can even say what they hope for their own future care. If time allows they will be able to get to know their future carers, work out plans for future schooling or work and how they will keep in touch with siblings and extended family.

To achieve this level of openess within the family, many parents need practical help to learn how to start talking and when to start? They want to know:

- How much detail to give?
- How much can very young children understand?
- How can parents answer awkward questions?
- Can they trust the children not to gossip outside the home?

Parents also have to face that opening up to their children about Aids often means talking about other family problems, for instance illness or death of the other parent, sexual matters, money - topics which in many households are not easily talked about with children. But if these subjects remain taboo it is virtually impossible to prepare children for the loss and changes ahead and they cannot be actively involved in planning for their own future.

As well as encouraging parents to do some straight talking, many of them also need help to learn to LISTEN to their children. They need to welcome questions, be on the alert for opportunities to drop important information into the conversation, give their children time to react and encourage them to ask more questions. There's no doubt that when parents "tune in" to their children, it makes it easier for them to put their fears and feelings into words.

Finally parents need to know that telling important information is never finished. One quick explanation will not do the trick. But their patience and willingness to talk it over time and again, to answer questions and to go at the child's pace, will gradually make it clear that the situation is not too terrible to mention. Problems ***can*** be managed. The unknown future ***can*** be faced.

Topic 2 of the training programme **covers the different stages of child development, what children can understand at different ages and ideas to help parents open up communications in the family. Topic 3 is about facing up to secrets in the family.**

3. PLANNING FOR THE FUTURE CARE OF CHILDREN

When one or both parents has HIV/Aids, it is unavoidable that family life will be disrupted at some future date. Although children cannot be protected from the distress of seeing their parents ill or dying, a great deal can be done to reduce their fears about what is going on in their home and, crucially, what will happen to them in the future.

But unfortunately when parents despair because the future looks so bleak and they don't know how to start to make a plan, children are put at real risk. In many cases children are not told what is happening until suddenly their parents become too ill to carry on or die before arrangements can be made. In some such cases senior relatives have to decide at the graveside where the children will sleep that night. Sometimes they are moved far away from everyone they know; brothers and sisters may become separated while other children have to cope alone without adult carers.

Without really understanding what is going to happen next its difficult for vulnerable children like these to hold on to their sense of identity and to keep hope alive that life will ever return to normal.

BUT if parents understand why it is so important to be open and to make plans before the crisis overtakes them, they and their children will be much stronger to face whatever happens in the future. This means being open with the children, involving them in looking at options and trying to make plans which they feel comfortable with.

Something encouraging to keep in mind is that Aids has an advantage over some other illnesses or accidental death - the course of the illness nearly always allows time to make plans - provided the parents understand what has to be done and are prepared to do the painful preparatory work with their children.

Safe and reliable arrangements can't be made overnight so parents need to look for solutions while they have strength and time on their side. If there is no obvious family member to take responsibility, parents will have to look further afield, for instance:

- is there a trustworthy member of the community who would supervise the older children and help them keep the family together in their own home?
- Are there any distant relatives who might take in one or more of the children and help them to keep in touch with siblings living elsewhere?
- Are there any welfare agencies working in the area who look for unrelated families to adopt or foster children?
- **Is there a local self-help group whose members would rally round to help the children cope?**

If parents can be helped to see that looking ahead will ***not*** make matters worse, they will find that the energy they wasted on denying their situation can now be used constructively. Like many other parents who have taken this brave step, they will feel a sense of relief and growing confidence that they CAN make a difference to the way things will work out for their children.

Very practical help on **Planning for children is given in Topic 7** of the training programme.

4. USING THE LEGAL SYSTEM TO MAKE PLANS STICK.

The best of plans can fall apart if they are not protected by the proper legal processes for naming guardians, making wills and safeguarding family property.

But when the Memory Project training programme got going it soon became clear that most families had little or no knowledge of the law; some people believed that making a will would hasten their own death; others were convinced that, as women, they had no rights under the law.

So the Memory Project now includes sessions on how to write wills, make formal guardianship arrangements and register ownership of property.

Understanding the law and dealing with people in authority might be a great challenge for parents who are struggling with illness and isolation. But with a bit of knowledge and encouragement many of them have somehow gathered their strength and tackled whatever had to be done in order to leave things well organised.

The importance of **using the law of the land to protect plans and property is covered in Topic 9** of the training programme. The Memory Project website also includes a simple guidebook on family law, guidelines on how to write a legal will and sample will form. (At present these papers relate to the law in Uganda but legal information for other countries will be added as they become available.)

5. WHO AM I? HELPING CHILDREN HOLD ON TO THEIR IDENTITY BY SAVING IMPORTANT FAMILY INFORMATION AND CHILDHOOD MEMORIES.

One way to help children survive the death of parents involves providing them with information which will give them a clear sense of identity and values to live by.

This includes making Memory Books which record personal information as well as giving details of the family background, traditions and beliefs. The written words and pictures, together with small familiar objects, saved in Memory Baskets or boxes, will bring back memories and help children to understand who they are and how they fit into their extended family and community

When the Memory Book was first shown to parents with Aids, they very quickly understood the value of writing down important family information. They realised that,

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if they died when the children were young, their words would always be there in the future, to help them manage without direct parental guidance. They wanted to be sure their children had the facts - information which would give them a sense of history and of belonging. But as well as personal history, many of them wrote about their values and beliefs and their hopes for how their children would carry themselves into the future,

As parents started to record their family history, some of them also began to collect small domestic objects, favourite books, photos, small possessions which had belonged to father and mother - not valuables, but everyday items which would help to keep memories alive and remind children of normal daily life. Some parents used specially woven baskets and others decorated tin trunks to store their treasure trove.

Although the original purpose of the Memory Book was just to make it easy for parents to write down all this vital information, it soon became clear that making Memory Books was also a sort of therapy - it gave parents the chance to remember happy experiences in their earlier lives, to describe their own achievements, skills and interests. They began to realise that they need not be remembered only as tired and sick but for their whole life experience - and that their ideas and values need not come to an end at their death.

Another plus was that, in many cases, once parents started writing their Memory Books and collecting the special bits and pieces for their Memory Baskets, their children became curious and soon they were drawn into the work. This gave parents a great opportunity to tell stories about the family and to explain the importance of carrying ideals and beliefs through to the next generation. So, as well as achieving its aim of helping parents to pass on important information about the family and individual children, The Memory Book has also provided parents with a "way in" to start to talk about their illness and the changes ahead. For many children this has been a far more comfortable experience than sitting face to face with the parents for a painful discussion. Because making the Memory Book is a long process, there are plenty of chances to go back over difficult information or questions which the child wants to ask again.

From the child's perspective, the Memory Book gives answers to questions they would have asked their parents over the years; it provides accurate information to help them understand their family background and all that has happened in recent times. It even helps them to keep contact with extended family and distant friends - who might otherwise be lost to them. Most important it helps them to really understand who they are.

Over time parents have come up with many new ideas which have been included in the revised Memory Book for Africa and as well as explaining how to get started, these guidelines include subject headings to help parents work step by step through different aspects of their family's life.

The whole process of **making Memory Books is covered in Topic 4** of the training programme and copies of the Memory Book in several different languages can be freely printed from the website.

OTHER TOPICS WHICH WILL BE COVERED IN THE TRAINING PROGRAMME INCLUDE:

- Facing up to family secrets – help to understand why open-ness usually works better than secrecy & how to break through the wall of silence.
- Changing relationships in the family – a look ahead to coping with feelings when a new partner joins the family or children have to move under another roof.
- Being prepared for the hard times ahead – helping children to be as prepared as possible for loss and change.
- Living responsibly with HIV. Because thankfully many people now live longer with HIV, new problems come up about who to tell, new relationships, and how to help children avoid risky behaviour.

(Please note that some of these topics are still in preparation and will be added to the website, along with other new material, as soon as possible.)

*****_The origins of the Memory Book are described at http://www.memorybooks.org.uk/memory-book-story - on this website._

******_The Memory Project was developed with the help of a group of HIV+ mothers who were members of a self-help group in Kampala, Uganda, from 1995 onwards._

*******_This website includes many of the original ideas and materials which were developed in Kampala, and now adapted to make it more user-friendly for self-help groups working without professional trainers. The website also includes new training material, translations of the Memory Book into different languages and provides opportunities for sharing ideas and resources with others who are working on the same ideas._

For more information you are welcome to contact us via the website:
http://www.memorybooks.org.uk/contact-memory-books