

"How can I prepare to bury my daughter when I also have to prepare to bury my son-in-law and granddaughter?" : the affects of HIV and AIDS on families and the work of the Family Support Network / The Terrence Higgins Trust.

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**“How can I prepare
to bury my daughter
when I also have to
prepare to bury my
son-in-law and
granddaughter?”**



The affects of HIV and AIDS on families and
the work of The Family Support Network

The Terrence Higgins Trust



**Not everyone is
themselves at risk from
HIV and AIDS but
anyone's life can be
affected.**

**Wives, fathers, sons and daughters,
grandparents and grandchildren...
all are having to learn to live with
AIDS and beyond.**

The Terrence Higgins Trust is often the first place people turn to when their lives are touched by HIV and AIDS. Anyone can call our national telephone Helpline and talk things through with someone trained to help. They could go on to receive face to face counselling from one of our counsellors.

The Family Support Network offers specialist support to families from the time of an HIV or AIDS diagnosis through periods of illness... through death and bereavement. Experienced family therapists provide counselling in person and over the phone. When necessary, they make home and hospital visits.

The Network provides an umbrella for families of people with AIDS throughout the UK who are able to contact and support each other. At the monthly support meetings the emphasis is on self-help and mutual support through sharing experiences.

The Family Support Network is another example of how the Trust provides a framework for people who want to do something to help.

The Terrence Higgins Trust



Eva Heymann works with the Trust's Family Support Network:

"The Network was born when the parents of a young man who died had appalling experiences and wanted to reach out to other families who were in a similar situation. Now the Family Support Group they started - the core of the Network - meets monthly, usually at the Trust since it's somewhere people feel they are safe talking about AIDS related problems.

One of the mothers said recently that the group is the only place where she feels she can talk openly. She said, *"Hearing about other people's problems and fears helps me - and knowing I can sometimes help them feel better makes me feel better."*

I visit people at home when they cannot get to us - for instance I called to see a mother who was too worried about her son's health to leave him.

I've found that people have an extraordinary ability to help each other at group sessions and capacity for giving support. I still get to hear stories about the support people give to each other. Once a father who lives in Yorkshire, who knew what it was like to suffer the stigma and isolation of having AIDS in the family, drove down to the south of England to help another man who was going through what he'd been through by sharing the pain.

Such support fulfils not just the needs of the families of people with AIDS. Once a prison visitor who was teaching the cello to a young prisoner came to one of the meetings. During a lesson, the young man had confided in her that he was HIV positive.

He was wondering whether to tell his mother.

He wanted to be reassured that if he told her there would be support for her.

You see it is important for the person with AIDS to know that their families can receive the right sort of help.

There are so many different circumstances in which people acquire the virus. One young man I met was pressured into going to a sex party with his mates - with awful consequences. Imagine the strain for a wife who

thought she was in a conventional marriage for over 20 years discovering that her husband is bisexual by being told he is HIV positive. The effects on others of a positive diagnosis are so often devastating. In the past 12 months I've noticed there are more and more cases involving children.

Families are having whole generations taken away from them.

Grandparents are having to bury their children and their children's children.

It is quite shattering when you realise that you are sitting with a grandmother whose daughter, son-in-law and grandchild are HIV positive. One death of a young close relative is shocking enough but when she asked me "How can I prepare to bury my daughter when I also have to prepare to bury my son-in-law and granddaughter?", I realised just how daunting the problem is.

Not so long ago, I was asked to see two girls aged seven and ten. They spent three weeks in London waiting for their mother to die. We were helping them in ways no-one else would.

In such cases we work closely with other agencies. For instance we asked the local authorities about having a house mother. The answer was "No". So we asked about fostering. They told us they didn't do so many of these things any more because of the cuts.

Also, the local social workers had not been trained to talk to children about death. So we had to sit down with the children and help them decide what they wanted to do after their mother had died.

Younger children are having additional responsibilities thrust upon them when an older brother or sister dies. That can cause additional problems - one teenage girl I met was so very angry with her brother for dying because she suddenly felt the weight of having to care for their aging parents alone.

Time and again, families that have been driven apart are reconciled by the person with AIDS. I remember a boy who had had a very unhappy childhood as his father had tried to beat his homosexuality out of him. He had failed at school and he left home. He turned to drugs - and then to crime to support himself and his habit. The father had banned the son's lover from ever coming into the family home. Yet as he neared death he asked to be allowed to die at home. Sadly this would mean that he could not be with his lover.

But even after what he had been through, the family ties were still strong. When he was close to death, his mother said it was alright for him to go. He asked her, "Mum, do you really want me to go?" She told him she didn't - but that she would always be with him. She was giving him permission.

The young man worried what his father thought of him and once asked, "Do you think my dad will ever be proud of me?"

He later told me that when the mother wasn't there the father ruffled his hair and gave him a hug.

When he was in the last stages of his illness, his eyesight fading and his muscles wasting, the father eventually asked whether he wanted to see the lover. Of course he did, and they spent 20 minutes together.

I was invited to the funeral and to a meal in the church hall afterwards. The lover came in and - in front of everyone - the father called his name and invited him over to sit and eat with the family.

The son had written the family a letter in which he told them, "Don't worry about me because I have now found the peace I have always wanted."

Out of an incredibly sad situation the family was united. As the mother said, "It has taken this to bring us together."

Eva Heymann was born in Germany and as a Jew experienced all the horrors of being shunned, marginalised and outcast during the War. After arriving in the UK as a refugee she became a nun and now counsels for The Terrence Higgins Trust Family Support Network.



The Terrence Higgins Trust



The difference the Family Support Network made for just one family.

**Andrew has thought seriously about
killing himself because of AIDS.**

He hasn't got AIDS; his Dad has.

Andrew is 13 years old.

His father, Martin, was diagnosed HIV positive seven years ago. Three years later he was told that he had AIDS. Until then Martin hadn't even accepted his condition let alone come to terms with it; the shock at the doctor's words made him so numb, he couldn't manage a tear.

Their own relatives and people they had thought of as friends turned against Martin, his wife, Joan and Andrew. Such reactions hurt them deeply.

They all thought that there was no one they could talk to as a family and as individuals - until they were put in touch with the Family Support Network. They received long term support with visits from Eva and over the telephone. Special needs - like Andrew's when he was thinking about suicide - are met with special counselling. The Network works with other agencies to ensure that people get all the help they need.

Martin has some advice for other families hit by HIV and AIDS: "Make contact with The Terrence Higgins Trust's Family Support Network - you don't have to struggle alone. I cannot thank the Trust enough for the support and help they have given me. It is a really good experience to know that there are people at the Trust who accept me and are willing to help me and my family."

He makes this plea, as someone who really knows just how devastating an AIDS diagnosis can be not just for yourself but for those you hold dear, "I would like to think that other families may experience the same support through contact with the Family Support Network."

This case history is real. The names have been changed to respect the privacy of the family involved.

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**The Terrence Higgins Trust is the leading
UK charity working in the field of HIV
and AIDS.**

When Terrence Higgins died in 1982, his illness was barely understood and his needs were not met. A group of his friends formed the Trust in his name to give assistance to anyone whose life is touched by HIV and AIDS.

We currently channel the efforts of over 1,500 people, most of them volunteers. Anyone - regardless of age, gender, race or sexuality - can call on us at any time whether on their own behalf or on behalf of a partner, relative or friend.

Recently we have launched initiatives especially for families. In conjunction with Barnardo's we produced two pioneering leaflets addressing children and their relatives affected by HIV and AIDS. We will provide a speaker to any interested schools and colleges.

We need money urgently to maintain these and our other services at even the current level, since demand for them all continues to rise. So it is up to you to make sure we are here when anyone wants us.

We have achieved so much thanks to the generosity of individuals in giving their time - and money.

There is so much more to be done.

Thank you for whatever you can spare.

The Terrence Higgins Trust, 52-54 Gray's Inn Road, London WC1X 8JU.

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