

A guide to being an HIV carer : love, relationships, hard work, rewards, social stigma / aNational AIDS Trust, leading partnerships to fight HIV.

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A guide to being an **HIV** Carer:

- love
- relationships
- hard work
- rewards
- **social stigma**

HIV *affected*

For every person infected with HIV/AIDS, there is at least one other affected person who finds him or herself involved as a carer.

Some may be frightened and unsure how to react; some will be reluctant to look for advice and support; but all will be trying in their own way to offer care for the person who has the infection.



HIV carers are:

- parents and grandparents
- children and siblings
- partners and lovers
- wider family
- friends

Social stigma

It is often hard to talk about HIV with family, friends or within the local community. There is still a major social stigma attached to HIV which puts families and carers in a 'double bind': not only are they looking after their loved ones, but they may fear losing their privacy or inadvertently revealing the identity of the person they care for.

Problems facing carers

- families and carers can be reluctant to seek out support services because they fear this means they themselves have failed.
- organisations meant to help do not have sufficient resources to provide the support required.



- statutory and voluntary bodies may feel that providing services in areas where there are fewer people with HIV cannot be justified.
- the needs of those affected by HIV are often not recognised.
- those who commission, purchase or provide services feel their priority is those who are infected.
- families and carers' needs can easily get lost in the gaps between different agencies' remits.

Their value

As new drug treatment become more complex, and people with HIV live longer with changing needs, so the carer's task becomes increasingly difficult. Yet without that voluntary, unpaid care, not only would the plight of those with HIV be acute, but costs to the statutory authorities would greatly increase.

Our aims

The National AIDS Trust's *Families and Carers Project* aims to:

- put HIV carers across the UK in touch with each other by providing a directory of contacts and establishing a network.
- offer assistance to organisations to establish standards in the practice of care, and in how to assess the needs of families and carers.
- press for these needs to be placed on the agenda of policy makers, statutory and voluntary organisations.
- help communities access information and services that are sensitive to religion and culture

How you can help

Please get in touch if you:



- have anything to contribute to the work of this project
- have any relevant information
- want to put the needs of HIV affected families and carers on your local agenda

Contact Joy Barlow at the National AIDS Trust on 0171 814 6767 or at the address on the back of this leaflet.

HIV carers face similar challenges to other carers.

But they may need to contend with an extra burden: the isolation and fear caused by the **social stigma** of HIV/AIDS.

The National AIDS Trust *Families and Carers Project* aims to help these carers.

National AIDS Trust

Families and Carers Project



Working to improve
support services for
HIV carers and families

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national aids trust
leading partnerships to fight HIV