

# Family Matters

## The great indoors the family living with HIV

*HIV has brought us closer together. The most important part of the day is around the kitchen table for dinner. We make important family decisions with our children. Maria*

Family members are all affected by HIV in addition to the concerns of normal family life. They may experience anxiety, sadness, anger, financial worries and the stress of having to deal with the medical system. In some families there could even be several members who are infected with HIV. They will worry that some day the HIV positive person will get ill and die.

HIV can cause stress and affect the way that families get on with each other. You will have to decide who, if anyone, you will tell about HIV, both within and outside your family. Family routines, like meal times, may need to be changed to fit in with taking pills and preparing different foods. At times, your family will have to cope with testing, illness and medical visits. You may be concerned about other family members becoming infected with HIV because it is in the home.

Every family is different and will need space and time to develop ways of coping with HIV. The family can also be a great source of love and support. Supporting each other by talking about HIV may make you feel closer and increase your sense of wellbeing. For those with HIV, having the support of your family can be vital in coping with infections and remaining healthy. Today it is possible for your family to manage HIV successfully with the help of a variety of services.

## What family members have told us about having HIV at home

**Parents:** Why me? Why my child? I feel lost. I don't know anything about HIV, I've got lots of questions. I'm worried about others finding out. How did they catch it? Where's the cure?

**Sisters and brothers:** I'm anxious and concerned for all the family. I'm angry with them for being positive. It's hard to keep this secret. I've got lots of questions.

**The HIV negative partner:** Keeping this secret is a great burden. Do I want to really continue with all of this? What can I do to help my positive partner? I have mixed feelings. Do I have the strength and commitment to survive all this for my positive partner, my children and myself?

**The child:** I'm scared of losing my mum or dad. I want to be open and honest. I'm scared of getting HIV and being sick. I'm confused about how my mum or dad is being looked after. They don't say much and I feel shut out. I've been told to use my own toothbrush, but I don't know why. I might have to look after them if they get sick. I feel lonely. How do I cope not telling? Who can I talk to?

**The HIV positive mum & dad:** Positive mums and dads have to work extra hard compared with other parents coping with family life. They have to work, look after their family, manage their own health, finances and housework, visit doctors, keep appointments, take medication - all of this even if they're feeling ill. There are many issues that are likely to cause anxiety for a positive mum or dad. They could include:

I'm trying to come to terms with this. Is this really what has happened? I have to focus on getting on with life. I'll be angry if I get ill. I'm relieved that my family seems to be coping. I'm scared of infecting my partner during sex. I don't want the family to tell anyone I'm positive. I'm living two different lives - one at home and the other at work. I need to tell white lies and it's really important that I get good at it. I'm scared about being rejected by other family members. Should I tell my kids? What if they reject me? I need to tell my parents, but I know they'll only be worried and anxious.

*HIV and feeling depressed  
puts an enormous strain  
on my family.*

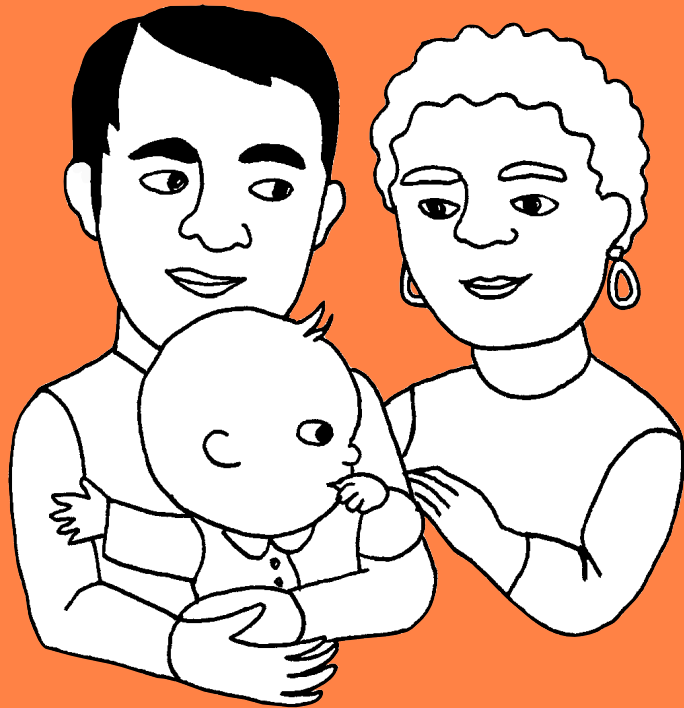
*John*

*I just try to do my best.  
I'm not good at this father thing -  
actually, yes I am, but it takes  
a lot of hard work.*

*Mike*

*HIV becomes the cause  
of all problems in the family  
and gets blamed for everything.*

*Lily*



## Telling and the HIV family

*I don't want to tell others because of my children. I don't want them to be  
bullied or ostracised. Theresa*

*I'm lonely and worried feeling other people will find out and judge my family  
and me. John*

*People will wonder how I caught it. Kris*

Families are likely to face the stigma that goes with HIV. They may feel ashamed that somebody in their family is infected. They are often anxious about telling others because they may be stigmatised and may not get any support if they 'go public'.

For a family, keeping a secret can be painful, lonely and stressful. Sometimes the family may need to tell a close friend, a relative, an employer, work mates, doctors or health workers. It's important to agree on who, outside the family, will be told.

Once you have worked out who's going to be told and who is not, you will need to agree about this as a family, and stick to it. This will help to avoid any bad feelings in the home.

If your child is HIV positive there's no legal requirement that you must tell their childcare centre or school. Some parents choose to tell the school principal especially if their child is taking medication during school time. It may also be useful to arrange some time for your child to meet other HIV positive children. This can be arranged through your counsellor or social worker.

## Talking about HIV with your child

*It scares me thinking about what will happen to my kids without me. Lily*

It's difficult for any positive mum or positive dad to tell their child that they have a life threatening illness. You will need to decide when the time is right for you and your family to do this. Some people tell when they are first diagnosed and others wait until their children are much older. Others choose not to tell their children at all. If you want to tell your child you can get help from an HIV/AIDS counsellor or social worker to work out what you're going to say.

Before telling your child, you will need to think about what support they will get after being told. Help could come from a close relative, other children of HIV positive parents, or your own support worker. If you decide to tell your child about HIV, here are a few tips that may be helpful:

- Talk truthfully about HIV rather than making up stories.
- Talk simply to your child by using words they understand.
- Don't tell every little thing about HIV in one big hit.
- Do the telling while you are up to it and feeling okay.
- Choose a time when the rest of the family is around so your child can talk to them as well.
- Check that your child understands that it's not okay to tell others outside the home.
- Before telling your child, remember that it is very hard for most children to keep a 'secret' and not tell others.

## Can I get infected?

A family member can get anxious if they think that by sharing a house with a positive person there is some risk they can get infected as well. Here's a quick list about sharing stuff with a positive family member:

Sharing stuff in the home	Is it okay?
Cigarettes	Yes
Clothing	Yes
Crockery and cutlery	Yes
Kissing- saliva	Yes
Mosquito bites	Yes
Sheets and pillows	Yes
Shower and bath	Yes
Tears and crying	Yes
Toilets	Yes
Touching, cuddling, hugging	Yes
Towels	Yes
Toothbrush or razors	No Best to use your own

For peace of mind and good hygiene always wash your hands after using the toilet or when preparing food, wear disposable gloves when cleaning up blood and other spilt body fluids, and wash any items with blood on them separately.

## Practical things Tips for coping at home

*I look after my family. I've succeeded in finding a full time job so I can build my son's future, which gives me all the ammunition to keep going and being optimistic about the future. Mike*

Talking about HIV within your family isn't always going to be easy. You may worry about losing the support of your family and even your children at times and becoming depressed and isolated. There are practical things you can do to make this easier.

## The positive family member

- Do family activities together.
- Learn more about your illness.
- Educate your family members about your illness.
- Always try to say things that you feel in a honest way.
- Get counselling to help you along.
- Agree with your family on who can be told about your HIV.
- Don't close doors on your friends and relatives and isolate yourself.
- Join a support group where your partner and family are welcome.

## The negative family members

- Talk together as a family about HIV.
- Ask yourself how can I help?
- Don't neglect to look after yourself if you're a negative partner.
- Get some counselling for yourself.
- See where you fit in with your positive family member and don't try and take over the show.
- Don't let the virus take over your life as a family.
- Expect the family to go through good times as well as some bad times with HIV.
- Get in touch with HIV/AIDS services that will help you and your family.
- Attend a support group for partners and family members.

## Home alone - getting support

*I find that I do not want to leave the house. Carlos*

*I worry about losing my job and the house. John*

Life with HIV is getting a lot better for many families since HIV treatments were made available some years ago. HIV for any positive person generally means having good health with periods of infection or illness. As a result your family will have to make changes from time to time to cope with all of this. HIV can throw your family's life into a tailspin at times and it can be hard to plan for the future.

It's natural if you are a parent to worry about your children and their future if anything should happen to you or your partner. Being a good mum and dad means this sort of thing does crop up.

There's help you can get if you're a family member living with an HIV positive person. Help can be both practical and emotional, and includes financial counselling, paying some bills and assistance with benefits and allowances, housing advice, homecare, family support, counselling and peer support. So there's plenty of help available and you needn't live behind closed doors! Call Pozhet on Freecall (Aust) 1800 812 404.