Don’t they make a formidable team?

Sally Gwengi was nine when she learnt her father was HIV

positive. She is now 18, and together, they are helping to

demystify the virus in their home area in Migori, Nyanza

Province

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When Sally Gwengi’s father told

her and her two sisters that he was HIV positive,

she knew with certainty that he

would die and leave them orphaned.

Her mother had died a couple of

years earlier and there were rumours

that “the virus” had killed her. The rumours

also predicted that it was just

a matter of time before their father

too died.

Sally was only nine years old then,

her older sisters 11 and 13. Though

she did not really understand what

HIV was, all she needed to know was

that it was a “bad disease” which

had robbed her of her mother and

would take away her father too.

“Our neighbourhood friends as

well as our schoolmates avoided us

and refused to play with us or even

come near us in case we infected

them,” says Sally.

She had prayed and hoped that the

rumourmongers were wrong, but

after her father’s disclosure, whatever

hope she had of living a

normal life was extinguished

**Peter’s story**

Sally’s father, Peter Gwengi, 49, discovered

that he was HIV-positive in

2001. Around that time, his wife’s health

suddenly deteriorated. It was then that

he learnt that she was HIV-positive and

had been on antiretroviral therapy for six

years, since 1995, a fact that she had kept

from him, perharps due to fear of rejection

and ridicule.

Peter learnt about his wife’s status is a

cruel manner.

“I was in the process of transferring

her from a local hospital to another health

facility where I thought she would get better

care and treatment when a nurse curtly

asked me why I was bothering, yet Aids

would kill her anyway,” he says.

This statement hit him like a thunderbolt,

and that very day, he went to see his

family doctor at the Aga Khan University

Hospital in Kisumu to find out if indeed

his wife was HIV-positive.

What he learnt shocked him to the core

— his wife had been diagnosed with the

virus six years earlier and had been on

antiretroviral therapy throughout this

time.

“I could not believe that I was the only

one who had been in the dark all along.”

The doctor, who had assumed that

Peter knew about his wife’s status, explained

that her health had gone downhill

because HIV care had been withdrawn

from his company’s medical insurance

policy, forcing her to stop routine antiretroviral

therapy.

Fearing the worst but determined to get

it over with, Peter got tested for the virus.

Even though he had prepared himself for

the worst, when the tests came back positive,

he was devastated.

For nine months, long after his wife had

died, he wrestled with denial, not talking

about the disease to anyone, not even

close relatives and friends,

and refusing to take the

appropriate medication.

Eventually, tired

of fighting a losing

battle, Peter finally

decided to accept

his condition and

do everything he

could to prolong

his life, if only for

the sake of his children.

He also decided to

go public about his

status. The first person

he approached

was his employer. He

made an impassioned

plea to his immediate

bosses, whom he

asked to make a case

for re-introducing HIV care in the medical

insurance scheme.

“ARVs were not free then and I was using

about Sh15,000 to manage the virus

every month, which was too expensive,”

he says.

Hi boldness paid off. Not only was HIV

care re-introduced in the medical scheme,

Peter was reimbursed all the money he

had spent on medication.

“If there were other employees living

with the virus, I am glad that I did something

to lighten their financial burden of

managing the virus,” he says.

This positive reaction is what gave birth

to the idea of starting an initiative that

would sensitise people around his home

area in Migori, Nyanza, about HIV/Aids.

“Many people still believed that HIV

could be spread through touch, therefore

those who had the virus were treated like

lepers,” he explains.

Telling his inner circle of friends about

his HIV status was easier than he had

expected, and even though he felt emboldened

about finally being able to talk about

it, he knew that he would need a double

dose of courage to tell his children. He explains

that his main concern was how they

would handle the news.

“Every time I decided to tell them, courage

would fail me and I would get out of

the house and weep, then tell myself that I

would do it later.”

One night in 2004, when Peter and his

daughters were having supper, he finally

told them.

When he was through, they immediately

broke into tears and one by one, left their

meals on the table and went to bed.

“I suspected that they had heard the

rumours and I knew that it was important

for them to hear about it from me so that

we could figure out a way to deal with it,”

he says.

Sally recalls this day vividly.

“His confession just confirmed to me

what people kept telling us about Dad

dying and leaving us orphaned. I was so

distressed and unhappy.”

Not even her father’s reassurance that

he would not die in the near future because

he was on medication and taking

good care of himself was enough to banish

her fears. Aware that his assurances were

not enough, he decided to hold regular

“counselling” talks with them regarding

HIV. Peter also took this opportunity to

talk to them about sex and contraceptives

so that they could make informed decisions

in future.

Says Sally, “It took us time, but eventually,

we came to terms with Dad’s condition,

especially since we now had a clearer

picture of what HIV is and that it is possible

to live for a very long time with it if

you take antiretroviral medicine and take

care of yourself.”

She says that even though the ridicule

and isolation by peers did not stop, the

bite was more tolerable, now that they

knew more about the disease and the fact

that their only parent was not about to

drop dead any second.

**Formidable team**

Sally is 18 now, and together with her

father, drives a sensitisation campaign to

promote positive living and acceptance of

people living with HIV. The Lake Victoria

Initiative, which Peter started in 2009,

targets schools, churches, and any other

forum that is willing to give them an audience.

While her father concentrates on a

“more mature” audience, Sally targets her

peers, whom she can relate to better and

whom she believes are more vulnerable to

the disease.

Their talks mostly centre on abstinence,

safe sex, managing stigma, as well as how

to support relatives and friends with HIV.

“I know from experience how difficult

it is to co-exist with others if you are HIV

positive or if a close relative has the disease,

especially if the people around you

are ignorant about the illness,” says Sally.

It is for this reason that she uses every

opportunity she gets to demystify the

illness, which she understands only too

well.

Sally, who scored an A-minus in her

KCSE examinations last year, will join

university next year, where she plans to

study economics. Though she suspects

that her studies will keep her quite busy,

she still intends to keep spreading awareness

of HIV and Aids.

According to the National Aids Control

Council (NACC), the infection rate of HIV

in Migori County is among the highest in

Nyanza Province. More alarming is the

high rate of infection among school-going

children. This has been blamed on

increased sexual activity with little sex

education for pupils.

NACC attributes this high rate of infection

to adults who prey on school children

and young girls due to the easy money

available along the beaches of Lake Victoria

from fishing.

SIGNED AN MOU WITH HIV

**Talking about how he takes care of himself,**

**Peter says that he maintains a well-balanced**

**lifestyle.**

**This includes a healthy diet, antiretrovirals,**

**exercise, adequate rest, and**

**dropping bad habits such as taking**

**excessive alcohol.**

**“HIV is a very jealous virus,**

**therefore, if you are**

**infected, you need**

**to be very cautious of**

**opportunistic diseases,**

**which can kill you very fast if not well managed.”**

**Stress, he points out, is also quite**

**dangerous and can undermine your health.**

**A well-established network of friends**

**and people living with HIV like him has also**

**played a significant role in ensuring that he**

**leads an accountable lifestyle since they are**

**charged with the duty of reminding one**

**another of what is expected of them.**

**When he found out about his status, Peter**

**was pretty sure that he would not remarry.**

**He has since had a change of heart however.**

**“I am considering it now that my children**

**are grown up and will be leaving home soonto start their own lives — loneliness is not a**

**good thing,” he laughs.**

**His first born daughter has completed**

**school and is working, while his second**

**daughter is in her final year at university.**

**That leaves Sally, who will join university**

**next year.**

**Peter believes that he contracted HIV in**

**the early 1990s when he worked as a field**

**officer, a job that kept him away from home**

**for long periods.**

**“I see no other way the virus would have**

**come into my marriage, although trying to**

**establish that is now irrelevant,” he says.d will be leaving home soon**