

Where AIDS victims go to die ...

— Photos by Michael Peake



ATLANTIC'S EDGE ... Situated on the farthest tip of Cape Cod, Provincetown is a celebrated resort of 3,500 where half the people living year-round are gay or lesbian.

PROVINCETOWN, Ma. — Former navigational officer Rick Wetherell, 41, planned his memorial service and even decided to be cremated.

Playwright Sinan Unel, 38, went to see his lawyer and had his will written out.

Salesman Ken Russo, 45, was so ill, the thought of death for him became a welcome refuge.

Death is the common thread that unites these men and this town. It is a living inevitable presence that permeates conversation, the politics, the religion and the social fabric of this tight-knit community.

But what also binds these three men is the use of counter-revolutionary anti-HIV drugs. The new superdrugs have not only created a renewed hope and cautious optimism, but it has also created a legion of survivors who are trying to come to grips with their new-found extension of life.

One in fifteen

In Provincetown, 50% of people living year-round are gay or lesbian. One in 15 has AIDS. It has the second largest AIDS per capita ratio in North America. It has been known as the place where gay men go to die, and several hundred have died here since the arrival of AIDS in the early 1980s.

However, with the advent of new combination AIDS drugs known as protease inhibitors, people with AIDS may be able to live longer.

In recent months Canadians have been able to gain access to these wonder drugs, which have been shown in short studies to shut down



Sharon
LEM

by the international health community.

HIV-status is not an issue here. Everyone is candid and uninhibited to kiss, embrace, hold hands in public and do as they please without being judged.

But the ironic twist for the people infected with HIV or AIDS occurs when you have prepared to die and you don't end up dying.

Ostracized from the mainstream public due to their sexual orientation, many who come to P-town — a celebrated gay resort of 3,500 located on the farthest tip of Cape Cod — have found this old fishing village to be a refreshing oasis.

You can walk for hours along the isolated slim stretches of whitesand beaches and seashore to watch the waves crash against the breakwall, smell the crisp autumn air, star gaze, or enjoy the night life of lively cabarets, theatres and restaurants.

You'll find many people strolling along the main beach-front strip of narrow roads lined with unique boutiques and historic Sea Captain's Gothic homes, quaint Victorian cottages that have been renovated into permanent year-round guest homes and inns.

People living in this tiny 19th-century fishing village are as far away from the U.S. as they can be, without being outside America.

Before building their homes on the Mainland in Plymouth, the 101 Pilgrim passengers on the *Mayflower* first landed in P-town on

The natural beauty and culture of this unspoiled area surrounded by the sea is both enchanting and serene.

Walking along the old wharf, fishermen can be seen unloading their daily catch of cod, pollock, lobster, squid, herring, blue fish and stripe back.

Celebrities like Norman Mailer and Barbra Streisand have homes here, while many other famous people often visit during the summer. Newt Gingrich's half-sister and lesbian Candace, made an appearance here Friday for Women's Week to speak on lesbian and gay issues.

For all its attraction, however, death is never very far away.

Wetherell, Unel and Russo were on the verge of dying last year. The trio were at the point where they were "starting to make preparations" for their deaths.

After months of faithfully taking protease inhibitors and other anti-HIV drugs, both made remarkable improvements to the point where they now feel well.

Wetherell, who retired two years ago from the U.S. National Marine Fisheries Service as a navigation officer, said his health has made a remarkable rebound since he began taking indinavir, one of the three protease inhibitors, last May.

"I was becoming increasingly tired and it was hard for me to keep up with my job. I was facing

lowered his blue eyes and his voice.

"I used to make decent money. I owned a house, credit cards, I shopped at Macy's — you know, all the pointless things in life," he said jokingly.

Dressed in a bright red Harvard University sweater and jeans, Wetherell begins to speak more slowly and his face becomes somber.

"I was at that point where I was going to get really sick and I knew it was coming because my T-cell count went down to zero (normal counts are between 500-1,200) and

my viral load was 50,000 (under 10,000 is good rate)," he said.

"After losing my lover and my career, a

‘I’m really thankful for the way I feel today’

— Rick Wetherell, about new drug treatment



But many are finding new life thanks to revolutionary drugs



na at that point in my life was death, right here," he says while sitting in a chair with his right hand placed two inches in front of his face.

Since I've been taking the protease inhibitor I feel well again and even better than I did when I freed from my job. I feel really strong, I don't have to take any naps in the middle of the day anymore. It's almost hard to remember when I felt good because when you're used to getting sick and you always feel like you have the flu good to feel normal again," he said.

I'm allowed to work part-time, but I can't make more than 80% of my past salary, so that's my big fear. It's an issue which should be addressed. I feel I could go back to work and be a full member of society, but the catch-22 is if I give up my retirement benefits, how will I pay for medication?"

Unel used to earn \$90,000 a year salary. Medicaid and federal insurance pay for 100% of his AIDS drugs. He's taken a part-time job at the Unitarian Universalist Meeting House as a buildings maintenance manager to help supplement his income and help pay for rent.

'New lease on life'

I'm really thankful for the way I feel today. It's certainly given me a lot of hope and now my back is out there," he says, smiling as he holds his right hand at arms-length from her.

It's both funny and amazing how life does change and I'm faced with this illness and I make a decision around my estate, my will and now I have a lease on life — I just hope these pills keep working," he said.

Unel, who has had full blown AIDS for 8½ years and suffered two life-threatening infections thought he was "almost dying."

"I was too sick to do anything. I don't even remember much. I was bed-ridden and it was like being in a coma.

"I had people come and take care of me and during all this, I thought about being scared of dying a few times," admitted Unel, who had even gone so far as to write out his will.

Unel, who has his drugs covered under disability and receives a few hundred dollars a month to live on, has been taking indinavir for more than a year now.

"I'm really happy with it because my viral load (amount of virus in the blood) has gone down to undetectable levels and I feel like I have all my energy back," he said.

The 6-foot-2 green-eyed blond said he's not placing all his eggs in the basket of these new drugs, in case he one day becomes resistant to them and they stop working on him.

"We've been living with 'we don't know' for a very long time and a lot of people when they become ill think that's it, we're going to die," said Unel, who recently won an award for a play he wrote on growing up in his native Turkey.

"Things are a little brighter now. I've been really happy and productive in terms of my writing and I'm not ready to die, so my plans are to wait and see what happens with these protease inhibitors because it's too new to decide if I'm going to completely change my life and get off disability and work again," he explained.

"It's not that people don't want to work, but if you give up your disability, you'd have to pay \$17,000 a year and who can afford to do that? That's the tragedy in this country, that I can probably never in my life get health insurance," said Unel, who receives \$600 a month in social security disability payments.

Russo, who has been taking indinavir in a potent combination of protease inhibitors since January, said his immune system has improved since his swiipe with death in May.

"I almost died in May. I felt like I was so close to it and I started making those kind of preparations to die," said Russo, who lost 25 pounds when he caught two opportunistic infections.

"In my mind I felt like it was time to go."

Russo, whose brother, sister and parents all live within an hour's drive from here on the Outer Cape, said he regularly met his family with his pastor, Reverend George Wells, to pre-



SEASIDE RESORT ... Provincetown's residents enjoy an uninhibited lifestyle.

and I thought I was going to die that evening and, you know, it didn't bother me," he said.

"It was so hard and I was in discomfort and a lot of pain and I thought if that's how it's going to be, then maybe it's time to check out now," Russo recalled.

"Now that I'm not sick and I feel better, dying is pretty scary."

Russo, who has seen hundreds of friends and acquaintances die of AIDS, said he relocated here five years ago to be near his family and friends.

"I would easily recognize hundreds of people's names of those who died of AIDS. I used to write people's names down, but I stopped doing that when I moved here," he said.

"It's funny, but the deaths seem to happen in waves and all of sudden, bang another one is gone. Emotionally and spiritually, there's not much reaction from me anymore when someone else dies. I'm being honest. I don't have enough time to

grieve one person in your life and you expect to lose people like your grandparents, and you have a remarkable amount of time to grieve and only one person to think about after a couple of

than "a miracle."

"Miracle? What's a miracle? Is it a healing? He's not cured, but whatever it was that was diminishing him, it's not there anymore. So healing? Yes. Miracle? Yeah, I think so," Wells said.

Wells, who pastors at the Church of St. Mary of the Harbor Episcopal (one of the five churches in Provincetown), has led a congregation of 125 through weekly worship for eight years.

Sitting in the church solarium next to the sanctuary, he makes no bones about the fact he serves "a very diverse community" of gays, lesbians, and heterosexuals, some of whom are infected with HIV/AIDS.

"P-town has been such a welcoming community to men and women, their lovers, friends and family of people living with HIV and AIDS," he explains.

"The grieving process as it relates to this particular illness is incredibly complex because the illness has no cure," he said.

"It causes people to grieve before dying occurs and this is called anticipatory grief — to live knowing you're going to die.

"What makes this illness unique is that in the times of Jesus, AIDS would be comparable to the way leprosy was treated where people were ostracized and sent away to leper colonies," Wells said.

"We're doing the same thing with people liv-



SINAN UNEL
"I'm not ready to die"

I've been living the don't know' for any long time

-an Unel, has full-blown AIDS

Living on the edge of America ... with AIDS

ed from previous page ...

community is com-
standing with and
or and working
the stigmatization
on, and for us who
fied as being part
we have to stand
r own denomina-
se the gay lifestyle
g debated within
Christian denomi-
e said.
ebate goes on, so
e fight for a longer

wn has been devy
y the AIDS pan-
we've lost lots and lots of
said Bill Clark, an intern
t at the Unitarian-Univers-
ing House in town. "With
se inhibitors, for the first
ear people talk about hope
— not about dying, but
't be settled until we hear
ure."

colleague, Reverend Jen-
ce, performs a memorial
most every other week.

erson here has lost 60 to
s or people they knew to
you can't even begin to
that," Justice said. "Pro-
itors give us hope, but it's a
hat brings many questions
here is a cure we can't for-
isn't over," said Justice, who is a

vincetown AIDS Support Group has
votal role in building a strong sup-
port for AIDS patients here.

Ben Stewart, executive director for the
group said support services and education is
focus for the group.

seen a shift in the last 10 years from
people living at the end stages of
providing strategies for people liv-
IDS in terms of nutrition, housing,
pects, prevention as well as res-
he said.

medical front, doctors, nurses, lab
as and social workers have been
vertime to help AIDS patients.

Alberts, an HIV-primary care doc-
Outer Cape Health Services Inc.,
umber of AIDS patients at the clinic
ased by 20% to more than 250 pa-
e the protease inhibitors were ap-
e sold last spring. Fifty of those
re on the protease inhibitors.
with HIV/AIDS tend to come here



AIDS WARRIORS ... Rev. Jennifer Justice and Rev. George Wells, inset left, have been helping AIDS patients like Pasquale Natale, inset right, who has been living with the disease for more than 10 years.

— Photos by Michael Peake, SUN

when they're sick because of the seashore,
clean air, clean water gorgeous sky and stars
and beautiful sunsets — it's a chance to live a
slower paced life in non-judgmental environ-
ment," said Alberts, whose partner can't han-
dle the side effects of the protease inhibitors.

"Now, the monkey wrench is that they're
not dying so easily because of the protease
inhibitors."

About 5% to 10% of patients are unable to
get access to these protease inhibitors be-
cause they don't have the money to pay for
them or they don't qualify for any entitlements
and can't get health insurance.

Alberts' colleague Dr. Ben Lightfoot said
"multi-combination therapy of protease in-
hibitors is changing the whole paradigm of
AIDS.

"I'm seeing a lot less patients at the end
stages of the disease. My patients are start-
ing to live longer. I think I was losing a lot of pa-
tients before we started using the inhibitors.
Now, I've maybe lost one patient since we
started using the multi-combination drug
therapy," Lightfoot said.

"The big bugaboo is that these drugs can

turn off the virus from replicating itself in
some patients now, but how long will this last?
We'll have to wait and see," Lightfoot said.

Lightfoot said the drugs do not work for
everyone and some cannot handle the side ef-
fects long enough to stay on the drugs.

Artist Pasquale Natale, 50, whose health
has rebounded since he started taking the in-
dinavir protease inhibitor, said he's "cau-
tiously optimistic" about the new combination
therapy because a year from now the people
on it can build resistance to it, so it won't work
anymore.

"Everyone had this kind of hope when AZT
came out and we knew then it wasn't going to
save lives either. Now this is the first time
we've had this kind of hope in a long time,"
he said, as he worked on a lamp in his studio in
the attic of the P-town's post office.

Canadian Sylvain Desjardins, 32, who was
originally from Montreal, moved to P-town
three years ago, but summered there for eight
years before that.

Desjardins, who has a permanent U.S.
green card to work and receives his AIDS
drugs free from an American program called

Act Now, works as a cafe manager
on the main strip of town.

Desjardins started taking one of
the three available protease inhibi-
tors in combination drug therapy in
September 1996. He started with riton-
avir, but stopped after a month
because of the diarrhea side effects.
He switched to indinavir, 10 days
ago.

"I feel much better, it feels like it's
doing very well in my body," Desjar-
dins said with a slight smile.

He says he moved to Provincetown to
"get away."

"I needed a change. I was just coming down
here to learn my English at first. I came here
because it's a gay resort area and I liked the
people."

He said he tried to learn English in English
Canada, but the people in Toronto were not
helpful.

"Everyone bitched at me and here the peo-
ple are patient, and they teach and help me.

Desjardins said he's not afraid of facing
death.

"I'm not scared of dying, it's no big deal.
I've been around too long and it's just a situa-
tion of life. It's like breast cancer and for a
woman, they simply have to just deal with it,"
Desjardins said.

"I'm hopeful. I believe that medical tech-
nology has made advancements and all the
research is starting to swing towards really
helping people with HIV and AIDS," he said.

The verdict is still out on the fate of these
new wonder drugs. But today, for the men like
Wetherell, Unel and Russo, they're simply
happy to be in P-town.

Ontario patients wait in suspense

The advent of new protease inhibitors has prolonged the lives of
those infected with HIV/AIDS in Provincetown, but experts are
quick to keep the optimism to a cautious level.

The triple-combination drugs, which work to boost the immune
system, have only recently been approved in Canada. The last one,
indinavir, was brought onto the Canadian market in late Septem-
ber.

The promising drugs are not a cure, but they may be the key to
turning AIDS into a long-term manageable disease because the
drugs block the AIDS cycle from replicating itself and suppress the
virus to undetectable levels.

In Ontario, there are about 1,000 people with HIV/AIDS taking
one of the three protease inhibitors in combination with older anti-
HIV drugs like 3TC and AZT.

In clinical trials, the potent triple-combination drug therapy ap-
pears to have extinguished HIV from replicating in infected people,
with some side effects.

Dr. Philip Berger, an HIV primary care doctor in Toronto, said

"The fear among HIV patients and doctors is how long the drugs
will be beneficial? It's a time of serious suspense and tension as we
wait for the next two to three years to determine what true benefits
the drugs provide," he said, adding the protease inhibitors don't
help everyone.

"I just hope this is not like the movie *Awakenings*, and the drugs
stop working after awhile."

Dr. Bill Cameron, one of Canada's top HIV researchers, is in
the midst of a 140-patient study which uses both ritonavir and sa-
quinavir.

"We're seeing that the treatment has improved the immune sys-
tem slowly, but steadily, in 90 to 95% of our patients," said Cameron,
of Ottawa General Hospital.

In the first month, about three-quarters of the patients got side
effects of numbness, nausea, diarrhea, but the side effects have
since disappeared.

"It's a little early to say, but these drugs have brought hope and
optimism to a large number of people, but we have to be careful not

Thomas Aspinwall
Mark Berman
Adrienne Brackley
David Brooks
David C. Burdette
Charles Chetani
Ronald A. Cooner
Robert Coskren
William Scoop Crawford
JoAnn Dickey
Stephen Fitzgerald
William Forlenza
Paul Gannon
Scott Hamill
James W. Kaufman
John M. Kelley
Michael Kerwin
William D. Lee
Todd Moore
Jeffrey Morrison
Michael Muller

Providence Journal

DEATH HAUNTS PROVINCETOWN **Volunteers became family in fighting AIDS**

TRACEY A. REEVES. Aug 16, 1992.

PROVINCETOWN --- Bruce Shipman and his lover, Philip D'Aduteuil, knew very few people when they moved here six years ago, but they figured they'd make new friends in time. It never occurred to them that they would find their best friends among the volunteers at the Provincetown AIDS Support Group. On July 22, 1987, D'Aduteuil and Shipman went to the Outer Cape Health Services clinic, in Truro, for an AIDS test. D'Aduteuil, usually energetic, had begun to feel tired for no apparent reason. His listlessness was compounded by bouts of diarrhea and sharp pains in his legs. The results three weeks later confirmed D'Aduteuil's suspicion.

He was HIV positive. Shipman was negative. D'Aduteuil went to a Boston hospital where he received counseling and a prescription for AZT - a drug believed to slow the onset of AIDS and prolong the patient's life. Meanwhile, Shipman became a volunteer at Provincetown AIDS Support Group's headquarters. "I knew there would come a time when we would need them," said Shipman. "I wanted to do something in advance so they didn't think I was looking for something later that wasn't deserved." Both Shipman and D'Aduteuil knew what lay ahead. They knew that most people with AIDS died a slow and agonizing death, though they both hoped and prayed for a miracle cure. There was none.

By early 1990, D'Aduteuil's virus had turned into full-blown AIDS. First, he developed shingles - an excruciatingly painful body rash - and pneumonia. Brain seizures followed. None of dozens of medications killed the pain in his head and throughout his body.