



Acclaimed actor Rupert Everett has pledged to help GAFFI raise awareness among health professionals and the public and will read out these two moving poems which have been written to better explain how patients with fungal infections feel about their condition.

He says: “I understand from the experts that fungal diseases tend to be complicated requiring specialised diagnostic skills. Only when it is too late is the diagnosis possible on clinical grounds, but even then many conditions overlap. The tragedy is that many of the best drugs have been available in some countries for 40-50 years, yet not where they are now most needed.”

Breathing

Mark O'Brien
1949–1999

Poet and journalist Mark O'Brien was born in Boston and raised in Sacramento, California. He contracted polio when he was six years old; the disease left him paralyzed from the neck down, and he used an iron lung to breathe. He earned a BA and an MA from the University of California–Berkeley. An advocate of independent living for disabled people, O'Brien was a frequent contributor to newspapers, writing columns on such topics as sports, religion, and disability issues. In 1997, he cofounded Lemonade Factory, a press that publishes work by people who have disabilities. His books include the memoir *How I Became a Human Being: A Disabled Man's Quest for Independence* (2003) and the poetry collections *The Man in the Iron Lung* (1997) and *Breathing* (1998), among others.

Two documentaries about his life, *Breathing Lessons: The Life and Work of Mark O'Brien* (1996) and *The Sessions* (2012) have been made. O'Brien died in 1999 of complications from bronchitis.

***Grasping for straws is easier;
You can see the straws.
“This most excellent canopy, the air,
look you,”
Presses down upon me
At fifteen pounds per square inch,
A dense, heavy, blue-glowing ocean,
Supporting the weight of condors
That swim its churning currents.
All I get is a thin stream of it,
A finger's width of the rope that ties
me to life
As I labor like a stevedore to keep
the connection.
Water wouldn't be so circumspect;
Water would crash in like a
drunken sailor,
But air is prissy and genteel,
Teasing me with its nearness and
pervading immensity.
The vast, circumambient atmosphere
Allows me but ninety
cubic centimeters
Of its billions of gallons and miles
of sky.
I inhale it anyway,
Knowing that it will hurt
In the weary ends of my crumpled
paper bag lungs.***

Mark O'Brien, “Breathing” from *The Man in the Iron Lung*. Copyright © 1997 by Mark O'Brien. Reprinted by permission of Lemonade Factory Press.

Source: *The Man in the Iron Lung* (Lemonade Factory Press, 1997)

POET Mark O'Brien 1949–1999



SLEEPCOMBING

Bob Devereux

Poet, painter and librettist, Bob Devereux ran the Salthouse Gallery in St.Ives, Cornwall for over thirty years. Since closing the gallery, as famous for its poetry and music events as its exhibitions, Bob has devoted his time to writing, painting and organizing the St.Ives Literature Festival, which occurs in May. Bob also runs the weekly Café Frug, a lively night of cabaret. In 2012 he was one of judges of the Project Life 'Funk! Fungi' art competition.

The poem 'Sleepcombing' was written during a short stay in hospital. It is worth observing, that Percy did not die that night, but was returned to the Old Peoples' Home because he was so noisy!

***Chests heaving, bubbling snores,
night talk,
Their old-man noises flood the ward.
This room provides no roost for rest.
I'm left here stranded on a ledge,***

***I word-walk edges, craving sleep,
combing the coast of memory,
hoping to find some remedy;
something adrift in murmuring.***

***At Porlock Weir the sea had dumped
pebbles, a frontier barricade.
Stone chatter sent us on a hunt
where shoreline groynes controlled
the waves.***

***My wife showed me a mythic beast,
torn from the cliff, aeons before,
warm in the stone; a rounded breast,
formed by the oceans tumbling,***

***a plump dove with a hero's head
resting his chin on feather folds;
sea crafted certain in his shape,
figure of Somnus from the deep.***

***I move but cannot feel my limbs.
Oh sleep... would be a gentle thing...***

***Percy's asleep, disturbing all
the ward.***

***He's off with dogs, where
walls dissolve***

***His chiseled face is like that bird's.
His harsh cries come as no surprise.***

***He's out there now, in silhouette
against the dazzling sheets of spray.
He calls his lurchers to him. "Heel
boys, heel."***

***His gown blows out behind him like
a wing***

***A voice intrudes says,
"Have you slept?"***

***A clattering trolley heralds day.
They bring me tablets in a cup
and tea and toast and marmalade.***

***I sit up contemplating eggs...
A curtain's drawn round
Percy's bed.***

Aspergillus in a well-loved pillow

Aspergillus is a common airborne fungus that causes fungal asthma, chronic infection after TB and life-threatening infection in leukaemia and transplant patients. Usually it is found in rotting leaves and compost, but it is also found in pillows and bedding.

This poem was first published in the special fungi edition of the international journal *Philosophy Activism Nature* (www.panjournal.net/).

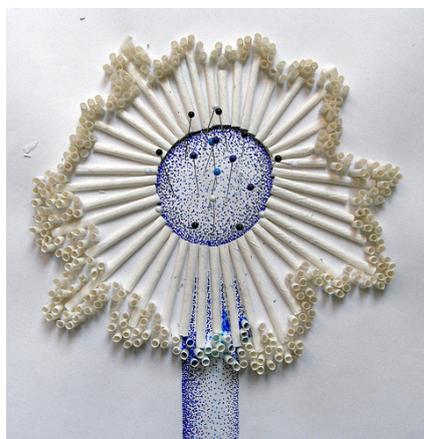
***All night
you breathe
my hyphae.***

***Your white blood cells seek,
then eat me; snip, stop
my stitch-up.***

***You won't face months
of coughing up buttons, dark
mucous plugs.***

***No x-rays for balls of my silks.
No drugs trying to heal where I left
all my needles.***

Caroline Hawkrige,
Writer-in-Residence,
National Aspergillosis Centre.



'Hope is...'

Aspergillosis Support Group Poem
written with Caroline Hawkrige, Writer-in-Residence, National Aspergillosis Centre.

Caroline Hawkrige has encouraged writing by patients, carers and staff during the monthly support groups and via the global online groups on Facebook and Yahoo, linked to the The Aspergillus Website (www.aspergillus.org.uk/)!

***Hope is when someone listens
to me,
when they hear what I say.
Hope is when tomorrow is
another day
and not just yesterday again.***

***Hope is daffodils and a bright
shining light
at the end of a VERY dark tunnel.
Hope is feeling happy or at
least normalised
when pain goes intolerable.***

***Hope is the spring that will
come soon
and bring along the flowers
that bloom.***

***Hope is that a solution may be found
to release me from the pain,
that there's better times to come.
Hope is having another day to spend
with my children and grandchildren.***

***Hope is friends out there we can
turn to
for 'been there done that' advice
& 'this is how I coped with it'.
Hope is successful treatment
and seeing tomorrow's dawn
and sunset.
Hope is breath for many years
to come.***

***Hope is not for today. For today, to
get out of bed, is all I can do
and its hours and hours before I can
lay down my head.
But hope is for tomorrow, when all
will be well
and this is the story I myself will tell.***

***Hope is like the sea that touches
every part
of our planet no matter where
patients live.
Together we can build
"A SEA OF HOPE"
that anyone & Everyone can
either dive
into or just "Dip their own toe".***

***Hope is to do some, to do it yourself,
that tomorrow is as good as today.***

***Hope is when someone listens
to me,
when they hear what I say,
when they hear what I say.***