

Robert Mc Crum (Author and Literary Editor – Observer) who was the guest speaker at the ‘Mick Doyle Inaugural Lecture’ – National Gallery of Ireland, Dublin, 25th January 2005, has kindly granted the Foundation permission to put his talk “Coming in from the storm” on our website sharing with the reader his experience in recovery from a major stroke at age 42.

Thank you. And thank you for coming.

I am, of course, deeply honoured to be giving **the first Mick Doyle lecture** here tonight,

A thousand thanks to Des O’Neill and Cora Lavin for organising it so superbly.

I hope this evening – a milestone for all of us – will be the first of many.

No city could be more apt for such an occasion.

Many of you will recall that *Dubliners* begins with that great first line:

‘There was no hope for him this time: it was the third stroke’.

Joyce once said that one of his reasons for leaving Ireland

was to escape what he called

the ‘hemiplegia of the will’.

Professor O’Neill tells me that this phrase captures

the indifference of the Irish Health Services to stroke.

When I had my stroke, I think there was the same ‘hemiplegia of the will’ in England.

But ten years of consciousness raising

and stroke awareness publicity

by the Stroke Association has begun to change attitudes

I have read that Mick Doyle was a man for whom obstacles did not matter.

‘Give it a lash’

That was his watchword.

I’m happy to make it mine here tonight.

I believe Mick Doyle, who, sadly, I never met, was a sportsman with a voracious appetite for life.

And a voracious will to live.

That seems to be the lesson of his incredible career.

‘Give it a lash’

That catchphrase was synonymous with the man, and

it’s also the lesson of his marvellous book:

Zero Point one Six: Living in Extra Time.

For me, the power of his story lies in

his extraordinary will-power in the aftermath

of his brain haemorrhage,

his refusal to give up,

and also his determination to focus on

the psychological dimension of stroke

during his rehabilitation.

I probably don't have his willpower
but I hope I do share his passionate interest in
the need for better stroke awareness and for better
post-traumatic
psychological assistance for stroke sufferers here in Ireland, in Britain,
and across the world.

My story is different from Mick's.
If only we could have met, and talked things over.....!
We would have found so much common ground.

Three things I know we would have shared:
First; we might have said that before the strokes we suffered, we thought we were
immortal.
Until I was forty-two, I had no personal experience of serious illness and very little
knowledge of death.
Metaphorically speaking, I went to weddings, not funerals.
To my generation, Death was as remote as the obituary pages of the newspaper.
Death, in the words of the poet Auden, was like the 'rumble of distant thunder at a
picnic'.
My life, and the lives of my generation, were hardly troubled by mortality.
Unlike our parents, we'd had no world war to bring some reality into the texture of
everyday life.
When I discovered all at once that I was quite definitely not immortal, you might ask:
How could I have been so stupid? So blind?

All I can offer is the charmed life of the fortunate baby-boomer.
It was a life that was, I suspect, not so very different from the lives of any number of
thirty- and forty-somethings in the west:
hedonistic, heedless, happy-go-lucky, helter-skelter.
From what I've been told, Mick's life was like that – and then some!
For me, it was on 29th July 1995
that my own merry-go-round crashed to a stop.
Somehow, I survived to fight another day.
I digested the painful lesson of my catastrophic physical collapse,
and embarked
on a slow and psychologically painful convalescence.

Mick and I certainly had that in common.
He has written movingly about this in *Zero Point one Six*. That title alone is
a typically irreverent response to the personal wipeout of a brain haemorrhage.

Second: we might have agreed that if you fall seriously ill you become
aware of the degree to which the whole world is terribly unwell.
This, I discovered, is not just a matter of physical decay.
Wherever I went I found people telling me of their illnesses, their
breakdowns, their crises, and their bereavements – their suffering.
By virtue of my "brush with death",
I'd become an involuntary representative of that world of the shivery hush
that precedes the arrival of the coffin.

I lost count of the number of people
who confided in me either the recent death,
or the profound sickness of someone near to them..
or their own encounter with acute illness.

Kirk Douglas wrote to me about his stroke in a spidery, half-legible hand.

Hume Cronyn, another veteran American actor, described his feeling on the death of
his wife, Jessica Tandy.

A woman whose husband had dropped dead one day in the kitchen
described, in the most moving possible terms,
the slow process by which she had become reconciled to her appalling loss.
And so on.

Perhaps this was something Mick and I would have talked about:
our role as emissaries of the dead.

**I think we'd both agree what a privilege it is to be granted the blessings of Extra
Time.**

And the third thing we might have done is talk about our shared experience of the
things called stroke.

Talking it over, at least in the first year, was a vital part of my
convalescence.

I cannot stress enough the need for stroke sufferers to meet their fellows.

Here I would like to pay tribute to my friend Donal O'Kelly – another great Irishman
– the founder of Different Strokes.

I should also say that my physiotherapist, Dreas Reyneke, who may be known
to some of you here tonight, is a man in a million.

So what, then, is the story I would have told Mick Doyle?

When I finally came to, some time during a long hot week-end in the summer of 95,

I was lying in the National Hospital, Queen Square

Recovering from a right-side haemorrhagic infarct

Paralysed on my left side

Barely able to speak

Stunned. Depressed. Tearful.

And confused.

Wondering what the future would hold.

If someone had said then that

In less than ten years

You will speak to such a distinguished gathering

In such a fair city

I would have said.....

I must be delirious!

So, looking back, I am grateful to the doctors

The physiotherapists,

And the various experts in many fields

Blood. Speech. Mobility. Fitness.

Who helped me come back from the dead.

Which – roughly – is how I felt that night in Queen Square

Ten years ago.

How I felt was not a whole lot different from
How I actually was.
Physically, I'd been poleaxed.
My left leg was immobilised.
My left arm hung from its socket like a dead rabbit.
I could not stand upright.
My speech was slurred.
In place of pain – I was never in pain – there was
An hallucinatory sense of detachment.
I was also oppressed
with an overwhelming fatigue.
There's nothing I can tell you
About the medicine of my stroke
That will seem original or different.
Many of you have seen scores of these.
You know how common they are.
How – in Britain – alone – 150,000 people a year suffer strokes.
From which one third will die.
How stroke occurs once every five minutes.
Or, to put it another way:
Some thirty strokes will occur here in Ireland in the course of this evening.
Some minor. Some major.
Some with barely detectable symptoms.
Some fatal.
You know all this:
Almost as bad –
You know the trail of chaos they leave behind:
Disability, Divorce, Unemployment, Despair.
What you don't know (perhaps)
Is how it feels...
What it's like to survive a bad one.
To survive an earthquake in your head.

The brain is only 1.4kg of grey matter
You could hold it in the palm of your hand.
But it's you...
And it's me,
My command post,
My HQ,
My language,
My Movement,
My window on the world.

Oscar Wilde once wrote:
'It is in the brain that everything takes place...
It is in the brain that the poppy is red,
that the apple is odorous,
that the skylark sings.'

So "the insult to the brain" of technical papers

Is not just a
Yah Boo Sucks
It's a colossal four-letter word.
The ultimate Expletive Deleted.
A cataclysm at the centre of who we are
Which takes some getting used to .
How I wish I could have talked to Mick Doyle about this:
we would have had things to say to each other here.
There are some things that only stroke sufferers know about.

The first thing – as I mentioned – is the unbelievable fatigue.
After my stroke I was so tired I could fall asleep
in the middle of a conversation.
At first, I could scarcely find the energy
to eat or wash
I was a zombie of fatigue
The smallest thing left me wanting to lie down and go to sleep.
To sit in a chair was exhausting.
Reading was impossible.
Even to watch television seemed like too much effort.

Another thing that no one talks about is: the Nights
Nights are when the patient imagines dying.
Nights are what emphasise our solitude and isolation.
We came into the world alone
No matter what prudent provision we make for the future
We shall leave it alone.
If I had a headache at night, or some unexplained pain
My first thought was
I shall be dead by the morning.

It was not all bleakness
There were some lighter moments.

One morning at 9.30 the bedside phone rang.
An official-sounding **voice said:**
“Holloway police here.
We have come to identify a dead body.
Where is Queen Street?”
Me: I'm not dead. I'm just a patient.
Cop: Sorry sir, but I have orders to identify this body.
Where is Queen Square?
Me: I'm not a corpse, thank you very much.
Don't you have a map?
Cop: I was hoping for a bit of co-operation and politeness.
Me (suddenly much better and alert): The kind of politeness, I suppose for which the
Metropolitan Police are renowned.

Looking back,

I must say that, surprisingly, the most difficult period was NOT at first, after the immediate crisis.

It was three months in, when I was beginning to mend.

That was the time my doctor – the great Richard Greenwood – identified as what he called ‘the rapids’.

The point at which I was feeling most frustration with my condition.

Once I’d got through the rapids
and into calmer water

I was on my way.

On the mend.

Then I began to make notes for
the book I wrote about my experience,

My Year Off.

I would dearly love to know what it was that inspired

Mick Doyle to write *Zero Point One Six*.

In my case, it was a cry for help, and an exercise in self-analysis.

I knew I was treated incredibly well in this NHS, but...

I came to understand that, for all the wonderful attention I received,
and for all the battery of tests to which I was subjected,
in the fruitless quest for the explanation to my stroke,
the nurses and doctors who came to my bedside
were ill-equipped to deal with me.

This was for two reasons,
half medical and half psychological.

The plain fact is that the specific dynamics of stroke are still mysterious: 40% of all strokes are unexplained.

Though we know exactly *how* strokes happen we are still in the dark about *why*.

In simple terms, this is because we are still quite ignorant about the brain.

Millions of pounds are being spent in mapping cerebral function.

But there are some parts of the brain that remain almost as obscure to us as the dark side of the moon.

To put it another way

The brain surgeon is like someone shining a pocket flashlight
into a darkened room,

hoping to pick out a single precious stone.

This is a problem for stroke medicine.

In medicine, generally, the contract between doctor and patient

is based on trust, on the assurance of certainty

and a supposition of expertise, of knowledge.

I believe doctors find it unnerving to have to take refuge in vagueness.

Not to be able to give patients a pill or an operation,

and send them on their way with a cure

goes against what we have come to expect of twentieth century medicine.

The brain remains the *terra incognita* of the human frame.

When my rehab specialist,

widely acknowledged to be the head of his profession,
sheepishly confessed to me that doctors are actually quite ignorant about the brain
it was oddly reassuring.
At least we were all in this together.

My neurologist's frankness was exceptional.
Most of the nurses, physiotherapists and doctors I questioned about my condition
were inclined to take refuge in reticence, a studied vagueness.
"Probably" I'd be fit in "about a year"
After six months, it "might" be "fairly clear" how much movement would return to
my left side.
Then, "perhaps" my arm would become "useful".
No one ever told me that, despite my initial incapacity, I would make a pretty good
recovery, go back to work and lead a fairly normal life.
As a result I became at first depressed and then defeatist.
If, ten year ago a doctor or nurse had told me that I would be able to write a book
about my experiences, contribute to the medical press about my condition, and even
speak to you here tonight,
I would have said they were mad:
at that point, three months into my recovery,
I was being told I might have to spend my whole life in a wheelchair,
an almost unimaginable thought.

What's more, like many young stroke sufferers I felt that no one understood what I
was going through.
That no one appreciated my predicament.

This, I think, is a crucial point:

The inhibition of professional competence is compounded, for stroke patients, by the
colossal psychological significance of the "insult to the brain".
I gradually came to realise that
the medical profession is not really equipped,
either formally, in training, or practically, in available time, to deal with this.

The emotional dimension of stroke is huge.
I cried a lot in hospital.
In hindsight, I see that unless you have been through the experience yourself
it is almost impossible
to provide counselling for stroke sufferers.

Until the medical profession realises that the outriders of the "insult" –
depression, despair, and a profound sense of personal bereavement –
are as important as the physical manifestations of stroke,
I suspect stroke sufferers will continue to feel a diffuse and semi-articulated
rage towards the doctors and nurses who come to their bedsides.
I note that whenever I speak to fellow stroke sufferers
it's this frustration – bitterness – rage (call it what you will) that surfaces most
quickly in conversation.
There are a lot of angry people out there

that hospitals and doctors are only dimly aware of.
You can of course treat the medical side of an illness,
but if you fail to address the emotional side,
you will never cure more than fifty per cent of the afflicted patient.

As a society, I believe we should devote more resources to understanding the consequences of what people are beginning to call 'brain attacks', to educating the medical profession to the hidden meaning of the word.

I seen now that nurses and doctors find the condition of stroke as frustrating as their patients.
They avoid making definitive pronouncements, because when it comes to the brain,
very few definitive pronouncements can be relied upon.
And besides, the truth is that it's Time which will heal the insult to the brain, and Time does not answer to busy NHS schedules.
It was to wrestle with these, and other questions, that I wrote *My Year Off*.

I think Mick Doyle and I came to the same conclusion: we had things we wanted to get off our chest.
The only way to do that was to put it in writing.

My Year Off was supposed to end my story.
File it on the shelf marked experience,
and leave something useful and informative behind for other stroke sufferers.

I assumed that, one day soon, my convalescence would end and I could put all this stuff behind me.
I assumed I would be able to close this chapter of my life so far, to turn a new page, and move on.
I was wrong. It was not to be.

My Year Off was published in Britain and then in America, with subsequent editions in Australia, Canada, and South Africa.
I was stunned by the reaction:
Overnight, it seemed, I became engulfed not just by the world's unwellness, but, more generally, by its universal pain.
The daughter of an old school teacher wrote to describe the "devastating psychotic breakdown" that had culminated in attempted suicide.
A well-known biographer described how illness had "sabotaged my mental and communicative powers".
And then there was this, from a mother in Wales:

"We, too, have become inhabitants of the world of pain. Our lovely daughter was diagnosed with leukaemia.
A year ago last week she suffered a stroke
Her right side was affected and she could not speak or swallow;
she went down to 7 stone.
Thanks to her youth she recovered her speech and her movement
She appeared almost normal on her 24th birthday, but.....

Back in hospital she contracted a serious infection and died of pneumonia...

The letter goes on:

“Now we are living in hell. Or rather, it is like living in two worlds: we see the “normal” world and we are able to integrate in it.

We do “normal” things, which provide us with some respite, but at the end of it all

We have to come back to the other world, our private hell.

Life does indeed go on, as everybody keeps telling us, but there is no joy in it for us, it is all mechanical.

My daughter used to cry pitifully in her worst moments and say “I want to be normal Mummy”. At other times she used to say “I wonder if I’ll ever be happy again”. and that is how I feel now.

I feel that I’ll never be happy again, there is nothing to look forward to.

The feelings are so complex.

Grief, although overwhelming, is not all.

There is also a feeling of failure at not having been able to save her and there is the guilt,

guilt that we are here when she is in her grave.

There is such deafening silence about this world of pain, about these people, like us, who have to live their lives in that world, being “brave” as it is called, perhaps putting on an air of “normality”, of “happiness” because otherwise it makes others feel too uncomfortable.” ENDS

I was still digesting the anguish of this terrible communication when, about a week later, I received this, from the North of England:

“My friend had a stroke last December.

She is paralysed on her left side.

She cannot walk or stand and has to be lifted with a hoist from her bed onto a wheelchair and from her wheelchair on to the toilet.

She has been terribly frustrated, angry, tearful, despairing and demanding throughout her convalescence.”

Even now, hardly a week goes by without someone writing to me, or telephoning, or emailing with their observations.

I find I have become a lightning conductor for that thunderstorm of physical calamity that is raging just over the horizon.

This, from a bookseller in the Midlands, is typical.

“I, too, suffered a stroke some ten years ago... I am aphasic, I know what I want to say, but have trouble in putting the words together....

Of course there is the relief that I have been spared to fight another day, but there are other days when I am possessed with an utter fury.....

And there is nobody to turn to.... No meetings, no contact, no help.

I have often felt a little alone in my affliction...”

These are not friends or relatives (though I've heard from them, too).
These are people living in what I've come to think of as the world of pain.
They are calling out to someone they think – rightly or wrongly – will understand
their plight and sympathize with it.
The incidence of physical suffering is a mystery;
perhaps sharing it lightens the burden.

And then there is the great enigma of that involuntary separation
inflicted by the death of those
without whom we would never have wanted to live.

Why am I repeating these stories tonight?

It's because I want to emphasise, as personally and vividly as I can,
that my story and Mick Doyle's story, are not unique.
We are just the more visible representatives of an army of sufferers across this
country,
and across the world.

I have had letters from widows, orphans, hospital-carers, parents.

I try to answer these letters, but, compared to the stories I'm hearing, my
experience has been trifling – as more than one correspondent has pointed out.

Sometimes, I feel ashamed to claim fellow-citizenship with these sufferers,
but there it is: They are writing to me and there's not a thing I can do about it.
In reply, I scribble banalities. "I'm glad you like the book. Thank you for
writing. Your letter touched me."

The truth is: it did.

As well as looking at the world through the eyes of someone who might
have died,
in these ten years I have acquired a quite new view of the world.
Of course I recognise that people will want to communicate with those they feel are
sympathetic to their plight,
but now I have come to believe something different.

It's this: that despite the stupendous journalism of feelings,
There is still a vast unarticulated story out there that gets no publicity,
a story of almost unendurable pain and desperation.

Sure, I've been to hell and back,
but these people are living in Hell every day of their lives
As TS Eliot puts it, "living and partly living".

Oddly enough, the more everything is reported, analysed, expounded,
categorized and explored in newspaper column after column... and
the more people feel able to express whatever they think,

about virtually anything under the sun,
the more deafening is the general silence that hangs over illness and ill-health.

There is a sea of horror lapping at the edges of the everyday world,
and these messages in bottles are floating in on every tide.

These are the messages from what I now think of as the world of pain,
messages that describe the suffering of strangers.

From this, I have learned three things,
First, that the world 's front-line pain
is the pain of AIDS, cancer, heart disease, and stroke (the bigger killers).
Behind the lines, there's the pain of despair, loneliness and loss.
The aching void in the lives of the bereaved and the afflicted.

Second, I now know that we are all, in some sense, in the doctor's waiting-room.
I used to be indifferent towards, and frightened of, illness.
Now I recognise it as part of the human condition.
Illness is OK.
There is nothing wrong with infirmity.
It's part of the way we are.

Third, finally, there's this recognition.
Despite the extraordinary progress of medicine.
Despite all the safeguards we have built into the way we conduct our lives,
we are still in the world of our ancestors.
In those fabled, far off, Celtic and Anglo-Saxon times,
life was characterised by the poets as
a sparrow fluttering out of the storm into the brightly lit mead hall,
circling through the laughter and the smoke for a moment,
before disappearing once more into the dark.

Sometimes, when I read these letters, and when I think of what Mick Doyle and
I have been through, I sense that dark just beyond the window. And I feel
grateful to be here, in the warmth and the light, out of the storm for a while.

So I think – I hope – that Mick Doyle would recognise what I've described.
Though I never knew him, I guess he would also want to say: "Come on,
mate.. Don't despair. Never say die. Give it a lash!"

That, for me was the inspiration for *My Year Off*,
The idea of transforming the rage of "Why me?", into the redemption of
"If me..."
It's also the message of *Zero Point One Six*.

In *My Year Off* I listed some practical Do's and Dont's for stroke sufferers.
Under Do's, I listed the following:

- 1) Try alternative therapies, acupuncture for example
- 2) Find out as much as you can about your illness

- 3) Take the initiative
- 4) Accept help from friends and relatives
- 5) Trust your body
- 6) Give Yourself Time
- 7) Meet and talk with other stroke-sufferers (Different Strokes)

My personal Don'ts are simpler and more fundamental:

- 1) Don't Despair
- 2) Don't imagine you are forgotten
- 3) Never surrender

Now, nearly ten years later, that never-to-be-forgotten summer's day of 1995 seems like a strange dream.

Sometimes I wake in the morning

And I wonder:

Did it really happen?

But of course it did.

And I have the deficits to prove it.

All I want to say tonight is

that a stroke is

Half medical and physical; and...

Half psychological and emotional.

It's frustrating to the medical profession

Because the usual doctor-patient contract

Diagnosis. Treatment. Cure.

Doesn't really work with stroke. But...

Don't forget that just because you cannot see and treat the wound

It's not there.

It is – and...

It's bleeding. And – deep down – it hurts.

Tonight, I have no suggestion or recommendation as to how to overcome this problem, but I would say that it's to the emotional as much as to the medical side that the profession should address itself.

Brains and hearts are what make us human.

When we listen to our hearts we hear many things. One of these was expressed

by the Romans as 'carpe diem'.

In my wife's translation – she's a classical scholar –

this comes out as 'Seize the carp'.

Mick Doyle might say: "Give it a lash!"

Or, coming back here to Dublin, there's

one of my favourite writers Samuel Beckett's

immortal formula from *Worstward Ho*:

'Ever tried, Ever failed. No matter. Try again. Fail again. Fail better.'

Failing better is something every stroke sufferer knows about. It is my hope that our stroke doctors will come to know it, too.

Which brings me to my conclusion.
It's one I'm guessing that Mick Doyle,
who wrote so well about his wife Mandy and his daughter Emma's role in his
recovery
would have wanted me to address in public.
Who knows?
Here goes anyway!

This, for me, is an extraordinarily hard subject to address – even now, ten
years on.
It means going back to the beginning,
to the first few terrible days in the aftermath of the initial “insult”.
Somehow I had to face up to what I'd been through.
To acknowledge how angry, bitter, and fearful I'd been in the first month of
recovery.

But then I found that there were other memories coming back, too.
Memories of the love and support of family and friends, memories of my
wife, Sarah's astonishing resilience in a very dark time for both of us.
Slowly, as I came to terms with my fate and as my book took shape,
I came to recognise that an event which seemed like a terrible curse
might even turn out to be a blessing in disguise.

The poet Coleridge observes somewhere that it's the convalescent who sees
the world in its true colours.
As a convalescent, I have been forced into a renewed connection with the
world, in all its pain and complexity,
and also with my body.
Into the painful realisation that, like it or not, I'm imprisoned in it.
I have learned, in short, that I am not immortal – the fantasy of my far-off
Youth.
Yet, strangely, in the process I have been renewed in my understanding of friendship,
family and, finally, the only thing that really matters:
which is love.
Thank you.

Robert Mc Crum
Author & Literary Editor of the Observer
**His book “*My Year Off*” (publisher Macmillan) recounts his experience in
recovery from a major stroke.**