



The
Huntington
Hydra

Bruce
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SAMPLE VERSION

First published in 2019
by Caparison
imprint of *The Recusant*
www.therecusant.org.uk

The Huntington Hydra is also available as a print book
as published by Caparison in 2019

Printed in Adobe Caslon Pro by
Printondemand-worldwide.com
9 Culley Court
Orton Southgate
Peterborough
PE2 6XD

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Selected by Alan Morrison
Edited and typeset by Alan Morrison © 2019
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ISBN 978-1-9993746-1-7

Acknowledgements

My grateful thanks are due to Alan Morrison, editor of *Caparison*, and established poet, for his help and encouragement in putting this anthology together. We have a shared interest in the fight against Huntington's Disease, and I have found working with him rewarding in both the personal and literary senses.

We continue to appreciate the ongoing support of both Anthony's family and mine, and those friends who continue to support us through these times. We also owe a considerable debt to the staff of the Royal Devon and Exeter Hospital and the local doctors and nurses for their ongoing support and vigilance.

Kate Davis and Nick Cooper of the Huntington's Disease Association, www.hda.org.uk, and Catherine Martin of the Huntington's Disease Youth Organisation, <https://en.hdyo.org/> have helped with my writing projects

Finally, Anthony himself has sanctioned the publication of this collection in the hope that it will contribute to raising awareness of HD, which is typical of the courage and resilience he has shown and continues to show.

All the poems in *The Huntington Hydra* are unpublished except for:

'Rooms in an Empty Palace' published on *The Recusant*, www.therecusant.org.uk August 2011

'Coriolanus Speaking' published as 'Sonnet for Coriolanus' in *Sarasvati*, Issue 29 2013, www.indigodreams.co.uk/sarasvati

'Becket's Last Prayer' published in my collection *Kaleidoscope* (Artificium, 2017)

'Us' and 'The Undefeated' are to be included in the *Momaya Press Poetry Review* 2018.

By the Same Author

Poetry Collections

Kaleidoscope (Artificium, 2017)
Raised Voices (Tohunga/Lulu, 2014)

Short Story Collections

The Guy Thing (The Linnet's Wings, 2018)
A Collection of Words (Words Magazine, 2018)
Odds Againts (Earlyworks Press, 2017)
First Flame (Sentinel Poetry Movement, 2013)

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Contents

Preface

About the H. D. A.

Poems

The Undeclared,	1
The Huntington Hydra,	2
Ambulance Days,	2
First Contact,	5
The News,	7
Hospital,	8
M.E. Revisited,	9
Kafka's Garden,	10
In Our Space,	12
Holding the Line 1&2,	13
For As Long As It Takes,	14
Darwin's Nightmares,	15
The Years,	16
Arriving Dilemmas,	18
Us,	19
There,	20
For Running Boys,	22
Sonnet False, Sonnet Real,	23
Summer Night Fish,	24
Wasted on the Young,	26
Invaders,	27
A Space in Time,	28
Caves and Fountains,	29
Stonehenge,	30
Paradise Somewhere,	31
Youtopia,	32
The Press and the Politicos,	33
An Unending Question,	34
A Finite Life,	36

M5 Afternoon, 37
The Day After the Battle of Hastings, 38
 War to War, 39
 Hostages, 41
 Reg, 42
 Inside In, 44
 Dusk, 45
 Culloden, 47
Hung, Drawn and Quartered, 48
Rooms in an Empty Palace, 49
 Durham Cathedral, 50
 Becket's Last Prayer, 51
 Battle of Towton, 53
 The Red and White, 54
The Taste of All I Knew, 55
 The Undeparted, 56
 Sonnet to Ronda, 57
Anticipating France, 58
 Losing Paris, 59
 Paris Faces, 60
A Hotel Garden in Montpellier, 61
 Aix-les-Bains Casino, 62
 Train to Geneva, 63
Girls in Windows, Boys on Bridges, 64
 Looking for Desdemona, 65
 Coriolanus Speaking, 66
 Marley's Warning, 67
 Something Turning Up, 68
 Rioja by Candlelight, 69
August Views Over Seaton, 70
 November Sonnet, 71
 January Morning, 72

Kaleidoscope

Preface: So Much The Better....

Privacy seems to be an issue which doesn't concern many people as much as it used to, judging by the cavalier way so many will reveal their activities, interests and private information on social media for all to see. However, for my civil partner Anthony and I, what is our business is generally kept that way, for a variety of reasons.

Huntington's Disease is perhaps the exception which proves the rule. Half of the poems in this collection connect directly to how Anthony and I have experienced the lead up to, onset of and subsequent development of Huntington's Disease; many of the others relate to our relationship and how it has made me think of it, as well as the places we have visited together and the lives we have lead. Yes, our business again, but not unrelated to what has happened and is happening in thousands of other lives, and we are both in agreement that if publishing the work can make even the tiniest contribution to raising awareness of the illness and what it does, then the result is worth the effort.

HD is the plague of the innocents. No-one brings it on themselves as a result of unfortunate diets or sedentary habits; no-one contracts it as a result of visiting countries without having had the necessary 'jabs'. Whether victims could be said to be culpable even in such circumstances is debatable, but in the case of HD, the issue doesn't even get off the ground. If one of your parents has the faulty gene, you will get it; it's that simple.

And it is not yet over. Yes, there have been significant research breakthroughs and a huge, interesting trial of a possible 'gene-silencing' drug is currently underway, but there remains no known cure or even medication to deal with HD, and it is clear that the drug will be some years in development. In the meantime, thousands of lives all over the world are being invaded and ultimately ended by HD. It is still happening, day after day, month after month, year after year.

Many of these poems are personal and revealing, and in the interests of the cause, I make no apologies for that—in fact, I think it can enhance their potential for communication. Writing them has helped keep me afloat on turbulent surfaces in recent years, and if they can do that for anyone else with similar issues of their own, so much the better.

Bruce Harris, Devon, November 2018

About the Huntington's Disease Association (HDA)

The Huntington's Disease Association (HDA) is the only organisation providing a dedicated service of advice, guidance and support for people in England and Wales who are affected by Huntington's disease.

Huntington's disease (HD) is a devastating, degenerative neurological disorder that causes progressive mental deterioration, significant behavioural changes and severe physical incapacity. It is a completely disabling hereditary condition that affects generations upon generations of families. Each child of a parent with HD has a 50% chance of inheriting the faulty gene; it doesn't skip a generation, so if a child tests positive they will, at some stage, develop HD. It's like tossing a coin.

Imagine having motor neurone disease, schizophrenia, Parkinson's and Alzheimer's disease... all at the same time. This is the reason HD has been described as 'the worst disease known to mankind'. It is an extremely challenging and complex terminal illness that needs expert care and round the clock support.

We run a regional Specialist HD Advisory Service to support those directly affected by the disease, and their families and carers, delivered by our HD experts and tailored to the individual needs of the families we work with. Our Specialist HD Advisers are a vital lifeline helping HD sufferers to navigate the complex care, health and emotional needs of the condition. Our advisers provide practical information, give advice and emotional support to families, identify local services, coordinate the organisation of care packages and answer crisis calls.

There are approximately 6,000 people suffering from Huntington's in the UK. For every person diagnosed another four people are at risk. That's 24,000 people whose lives will, at some point, be turned upside down by the anguish of waiting for a diagnosis, or taking their chances without. These people are referred to as 'at risk' and may exhibit early signs of HD, such as slight uncontrollable muscular movements, stumbling and clumsiness, lack of concentration, short term memory lapses and sometimes aggressive or anti-social behaviour. They are frequently unfairly judged as appearing drunk and uncooperative, which is often compounded by depression and thoughts of suicide.

Supporting individuals and families is our core focus. Our 23 Specialist HD Advisers are currently working with a total of 13,639 people affected by HD across England and Wales. Many of these are HD patients, but they also help those at risk, and their families and carers, who shoulder the heavy burden of caring for their loved ones. Although there is currently no cure for HD, the specialist expertise we provide empowers patients and families to manage the condition, and helps to reduce the extreme fear and isolation they often feel.

Please visit www.hda.org.uk for more information on the disease and for ways to donate to the Charity.

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The Undefeated

To see him lose the ephemera of pleasure,
the taken-for-granted, every day joys,
an impromptu rummage around in the kitchen
conjuring a meal from whatever's available;
a morning stroll along the promenade
just taking in the sea, view and air;
an absorbed book reading, cover to cover,
engrossed in science, narrative, polemic;
a one-off visit to the undiscovered
just for novelty, curiosity, interest,
is enough of itself to be breaking my heart,
such dull, mindless, arbitrary cruelties.

But there is, always, his patient resilience,
his undemonstrative endurance,
his stoic insistence on preserving remainders,
holding on to existing consciousness.
He is drifting from me like a boat on the tide
and I know our waving and talking must fade
but courage and hope are benign enough parents
for the nutrition of continuing defiance.
After thirty odd years, I am still learning
the great depth and breadth of the being he is
and the excesses of Huntington intimidation
may yet be met by more than their match.

The Huntington Hydra

The legendary Hydra, a many-headed monster remained untamed in the depths of its lair, deliberately breathing out killer poisons and as an analogy of Huntington's Disease it fits in every dismal particular.

The largest, most vicious head of all can bypass the body to attack the mind with an added venomous visceral twist that every victim lives with the knowledge of a parent being the source of the curse.

The head which twists and twitches the limbs creates the grotesque dance of chorea and taken for granted movements of ease are subjected to a new external control which seeks to destroy elemental confidence.

And those inclined to a refuge of reading the literature fuel of personal hours, find print made meaningless, emptied of shape, and hours cast back into a void of time like sudden arbitrary redundancy.

Wanderers, adventurers, curious travellers, who seek to explore, venture, discover, can do so no more; the boundaries surround, and confinement is armed with restrictions as the Hydra snaps the cell doors shut.

And, if not enough, one head of the beast waves away the daily dietary freedoms and, regardless of preference and taste, dictates the possible and denies the choices stealing even the minutiae of liberty.

Hercules is much more of a myth than a man
and the strength and resources of my partner and I
are inevitably modest compared with a legend
and striking back at multiple assault
is a draining dispiriting business.

But no-one is ultimately alone or deserted
while scientists work to defeat the Hydra
and like multiples of Hercules, thousands will fight
to slash the heads down one at a time
until the beast is broken and we are all free.

Ambulance Days

Over twenty years ago now, I still
paused whatever I was doing for a smoke,
suspending the task to contemplate the infinite.
Attacking weeds, while ecologically sound
and advantageous to bone and muscle
is not, of itself, intrinsically fascinating
and best punctuated by meditative pauses
while imbibing a weed of a different nature.

And that was, I thought, the mood of the day,
routine, mundane, a constructive way
to pass an idle hour, while my partner worked
at home, a rare innovative practice.
Half an hour later, life twisted to turmoil,
my chest pains tightening as my body sweated
and everything I ever was or might be
faced with a sudden massive question mark.

On a stretcher, I could see only clouds and trees
as if life's remains were hurrying on by
and the siren's tumult was an accusation
of self-induced damage, produced by my reckless
inability to properly read the warnings
but it eventually proved the ultimate warning
and linked to a monitor in intensive care
my casual receptors got the message at last.

Two more scares were false alarms; it seemed,
for the time at least, I had won my life back.
Seventeen years on, and it was Anthony's turn,
our roles reversed, me dialling the number
and him frozen some way between hope and terror.
Now I had to sit in the watching chair
as his consciousness drifted, paramedics attended,
and the siren declared a suspension of norms.

Ambulance days have their silver linings,
unambiguous, positive, undisguised:
mine a warning with a volume of a bellow,
my partner's a precursor of a wider problem
then unsuspected. Foundations are shaken,
lives flung in the air like miniature big bangs
and when the dust and the debris have settled
every landscape is changed forever.

A Hotel Garden in Montpellier

Most multi-coloured birds go quiet in the night
and the vast imperial trees sway in stately waves
but the creature medley noises still echo in the air
and leaves and branches hum like far distant conversation.
Behind them and beyond, the busy car whoosh fades
and the bar's discordant voices patter like random splashes.

This town has had magicians working in the routine;
the daily trams unload in the shadow of Three Graces
and people in the square, pleased with where they speak,
are free of malodorous cars, like marauding circling beasts.
Here, the working day doesn't gulp the living down,
sending red-eyed people home, drained zombies in the dusk.

Nature frames here patiently the clatter of human dramas
in something like a partnership, a careful co-existence,
both spontaneous and contrived in this garden through the night.
Detach it from human and red tooth wildness comes soon;
take the natural away and the concrete marches on
with exposed and harassed people breathing fetid fumes.

Whose time lasts, whose time passes, whose the interruption
of the planet's fate in progress, hegemony of us or it?



Bruce
Harris

Bruce Harris started writing creatively in 2004 after a career in teaching and educational research, including extensive research-based publications. Since then, he has been consistently successful in short fiction and poetry competitions, and extensively published in print and e-zines. He is author of several short story collections, *First Flame* (2013), *Odds Against* (2017) and *The Guy Thing* (2018), and poetry collections, *Raised Voices* (2014) and *Kaleidoscope* (2017). For personal reasons, he is donating the takings from his published books to the Huntington's Disease Association.

All proceeds from the sales of this book will be donated to the Huntington's Disease Association (HDA) www.hda.org.uk

“Harris has his own compassionate, deeply humane and topically eclectic poetic personality that stamps its mark on the page”

Alan Morrison

Price: £3

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