

EXTRACT FOR THE PEOPLE'S BOOK PRIZE

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John Vllens

I was born with the Ebstein Anomaly heart-condition. In my life so far, I have already required three operations. When I was 20 I suffered from brain damage in a traffic accident, the head injury I sustained put me in a three week coma, resulting in a bipolar disorder. My present day contentment, and coming to terms with the heartache I had from disappointed ex-



Picture by: Tim Robinson

partners, has been given to me by the hard work of my mother's tireless care, family, friends, and my psychologist. Furthermore contentment has come from all the very kind people I met, who helped me to create my life coping mechanisms, which I would like to share with others afflicted in similar ways.

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How to use this book

I have highlighted and drawn from my personal experience, key relevant morals to help you to improve your state of mind, outlook, and physicality. Throughout my memoirs is a list of numbered anecdotes. These numbers are linked to the final section of this book where the anecdotes are elaborated and the coping mechanisms are explained further.

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Foreword

By John's mother

There cannot be many greater sadness of the sort which never, for a minute leaves you, than that of a mother watching her beloved child suffer and, furthermore, knowing that his life expectancy is poor. As a child, from three years old onwards, having been diagnosed with a rare and potentially fatal congenital heart disease, John was constantly admitted to hospital for endless tests, often painful and always frightening. At home, he was often unwell and, owing to the restrictions imposed upon him, was frustrated by not being able to keep up with his peers. His never-failing sense of humour, however, kept us all laughing in spite of everything.

The next major episode of him whom I came to refer to in my thoughts and prayers as my 'Heartbreak Child', was the road traffic accident which nearly claimed his life and put paid to any hope of John leading a normal life. Then he was twenty.

He has written this account of his life in order to give hope and determination to those who, like him, have hit rock-bottom and have no reasonable hope of a happy and fulfilling life.

Having, for many despairing months and years, witnessed John's illness and slow struggle to recover, I now, with our loving and ever supportive family, rejoice in the peace and happiness which is his today.



Stephanie Gauntlett- John's Mother

Preface

Sometimes we are our own worst enemy. Many feel that life and other traumas are usually of one's own doing, nonetheless we can often fall victim of fate. John Ullens knows this all too well. By recalling his past, John, with the advantage of hindsight has identified where he went wrong, yet more importantly, how he managed to pull through life's strife with a strong will. John identifies some essential coping mechanisms that can be utilised to overcome many of the fundamental inhibiting elements of mental and even physical disabilities. These can be utilised by sufferers and their supportive friends and family alike. Rehabilitate your mind, mentality, and physicality.

'I proved them wrong'.

John Ullens

Understanding

Your first guiding steps start here...

Understanding your disorder is vital to your understanding of yourself. It is also vital in helping others to understand you, so that they can help you to recognise your symptoms and aid you in accessing the appropriate care and treatment.

To the friends and families of sufferers, and the wider world...

Many don't understand how a sufferer can feel and who a sufferer may be. Sometimes it is hard to recognise a sufferer and it is possible that someone you know might have a bipolar disorder or is prone to developing one. Between 1 and 2 people out of 100 have the condition. I developed the condition through accident trauma, but many develop it via less obvious stress triggers. So be conscious when you read this section, of spotting any signs and symptoms of the illness, which could be relative to other family members and even friends. Bipolar disorder is hard to diagnose and treat, if you can educate yourself and spread awareness from this knowledge, it could greatly benefit sufferers and help to develop others recognition of the illness.

Types of Bipolar Disorder

Bipolar type I-

- Sufferers have had at least one manic (high, elated) episode, which has lasted for longer than one week.
- Some people with Bipolar type I will have only manic episodes, although most will predominantly have periods of **depression**.
- If untreated, manic episodes can last for 3 to 6 months.
- **Depressive** episodes last longer- 6 to 12 months without treatment.

Bipolar type II-

- Sufferers have had more than one episode of severe depression, but mainly only **manic** episodes- when you suffer from mild mania this is called '**hypomania**'.

Potential Bipolar 'Cyclothymia'-

- The mood swings are not as severe as those with a full bipolar disorder, but can be longer. This can develop into a full bipolar disorder.

(RCP, 2010).

The Symptoms

Depression - It is natural for everyone to experience depression. However, for bipolar sufferers, the feeling is hard to overcome and takes over healthy daily functioning.

Behaviour	Wellbeing	Emotional	Rational
Difficulty in starting or completing things Crying a lot or feeling like you want to cry Avoiding contact with others	Great loss or gain in weight Lacking sleep- constantly tired Constipation Going off sex	Constant unhappiness Great indifference Tearfulness Easily agitated Lack of self-confidence Suicidal thoughts	Negative thoughts Daily tasks become hard Lack of concentration

Mania- With mania you get an extreme sense of well-being, energy and optimism. Yet this intensity of emotions affects your thinking and judgement. You can have warped ideas of yourself, make bad decisions, behave in embarrassing exaggerated manners, and be harmful or even dangerous to yourself and others. It can make it difficult to deal with life and normal daily tasks.

Behaviour	Wellbeing	Emotional	Rational
Making unrealistic plans Moving quickly Talking quickly Making Spur of the moment odd decisions Reckless money spending Less inhibited	Full of energy Unable to sleep More interested in sex	Very elated and excited Irritated with people who aren't as optimistic as you Feeling over important	Constantly thinking of new ideas Moving quickly from one idea to another Hearing voices that others can't

When in a manic episode, you may often not realise that there is anything wrong- although others will. You may even feel offended if someone tries to point this out to you. You increasingly lose touch with other people's feelings. (RCP, 2010).

Causes

There is no denying that our understanding of this illness is still in its infancy. Unlike physical disabilities, psychiatric disabilities are often hard to asses as there is no obvious broken bone, wounded limb, or maimed organ that stands out to focus on. Many have turned to the brain and an imbalance of signal sending cells, sending extra signals to other cells, causing psychologically overactive or extreme behaviour. This is a likely cause of many psychological disability cases, however just as the mind is complex; so too is the brain, with

medical experts conjuring new ideas and theories, still yet to find the true cause. The following are considered to be the most likely elements in causing the disorder- many believe it is a culmination of these biological and environmental elements that cause bipolar conditions:

Genetics-

There is evidence to suggest that bipolar disorder can be inherited and that there is a genetic vulnerability to developing the illness. If a parent or older relative close to your bloodline has had the illness, the likelihood is that you will be more genetically prone to developing the illness than someone who does not have a family history of bipolar disorders. The genetic inheritance is thought to be that of the neurotransmitters. A relative may have had a high, low and/ or general imbalance of a specific neurotransmitter such as serotonin, norepinephrine, or dopamine. These are the key chemical links to mood disorders.

Stress-

Stressful life events are thought to be the main element in the development of bipolar disorder (when the genetic foundation is present). You cannot specifically define these stressful events, as they are often personal to the sufferer, and while some things may stress one person, they may not stress another. However, a dramatic change to a healthy structured life is a typical stress trigger; the following could be common triggers:

- The experience of death
- Loss of a loved one
- Divorce
- Loss of a job
- The birth of a child

Stressful life events can lead to the onset of symptoms in bipolar disorder. Once the disorder is triggered and progresses, the cycle begins, and the psychological and/ or biological processes take over, keeping the illness active. (RCP, 2010).

Treatment

There are several mood stabilising drugs that can be prescribed to people with bipolar disorders dependent on their type of disorder. Lithium (a naturally occurring salt) was the first effective mood stabiliser and has been successful for many. However, treatment with Lithium or any other mood stabilising drugs should be started and recommended by a knowledgeable psychiatrist. Mood stabilising medication often has its setbacks, and it can be hard to find the right daily dosage for you, to balance out the bipolar behaviour. I and my wife, Lai Kam, are still yet to find the right medication for us. However, this book aims to inform you of all the other possible ways you can rehabilitate yourself along with your medication, and help create a balance.

Coping

After reading this section you have already completed the foundation of your self-rehabilitation by becoming more psycho-educated and informed about your disorder. Nonetheless, here is a rundown of the other methods that will be discussed later on, and will help you to gain more control over your mentality, creating a healthier mind:

- Psycho-education- awareness of your disability
- Mood monitoring- helps you to recognise when your mood is changing
- Mood strategic control- thought mechanisms to help you tame your mood swings
- Developing simple and general coping skills
- Cognitive behavioural therapy for depression- training yourself to understand a situation in a positive, clear, rational manner

(RCP, 2010).

Now that you are hopefully on your way to greater self-understanding, I hope that my story will enhance your acceptance of yourself and show you that you are not

alone, and that there are lessons to be learned by reflecting on your past and unearthing the initial triggers of your disorder.

Obstacles and Recovery

Cardiac and Recovery

I was born a heart disease baby. It became clear to me in my early years, as I became out of breath very quickly, and could not keep up with my peers, that I would need to develop a coping mechanism in order to remain active. I would need much assistance and care from adults, whose sympathy and love I made my mission to obtain. This early study of character, and learning how to make friends, would help me for the rest of my life. If you are kind to others they will be kind to you or, as my great-grandmother used to say 'you reap what you sow'.

- 1. The world isn't against you, make and maintain good relationships with friends and family. Only good can come of it.**

In my early thirties, an operation to correct my cardiac anomaly became available. I had the procedure performed, at the Royal Brompton Heart and Lung Hospital, by the French surgeon who had very recently pioneered it. At the time, I was on vastly increased psychiatric medication and I had

brainwashed myself not to care too much about surviving the operation. Maybe I was in denial, I just decided it was better to let the medical professionals get on with their job and keep myself distracted from being too serious; my recovery was painful and not without its set-backs.

2. A principle I often adhere to is that by keeping one's spirits a little carefree there is a better chance of a positive.

However, my most vivid and heart-warming recollections are of meeting, after the open-heart surgery, other heart-patients who taught me more about the streetwise survival of those disabled in our way. Isn't our memory wonderful in always selecting the rosy side of the past?

3. Isolated? You are not alone. There are many like you out there. Consider yourself 'different' and 'unique', but not alone.

4. A healthy outlook encourages a healthy lifestyle; a healthy lifestyle encourages a healthy outlook.

I believe that, with reasonable care, gentle exercise, a healthy diet and a positive outlook, my heart could keep on going much longer than expected! One eminent cardiologist reluctantly reassured me about my inability to stop smoking, saying that my operation had been so successful that, for me, smoking now carried the same risk as it did for other healthy people. I learnt that I could exercise a little, often resting to recover my breath, and the cardiologist approved. Nowadays, I have regular check-ups of my heart condition and pacemaker, at the Heart Hospital near Regents Park.

Brain-injury and Recovery