Making Sense of Paranoia

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Personal, Political and Professional Perspectives

Edited by

Peter Bullimore, Ian Warwick
and Kenneth McLaughlin

Cambridge Scholars Publishing

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FOREWORD

MARIUS ROMME

There is one name in particular that will appear several times in this book, that of Peter Bullimore. In addition to his own chapters, he is mentioned by many other contributors as a key influence in their recovery from paranoia. It was his vision to bring all of us together to compile a book on paranoia from a variety of perspectives, but one that foregrounds the personal narratives of those who have suffered trauma and paranoia.

In 1996 Peter set up the Sheffield Hearing Voices Group. It is now the longest running hearing voices group in the world. He also founded the National Paranoia Network with Dr Terence McLaughlin in 2004 and in 2008 set up the first hearing voices group in Athens. It is no surprise that many owe him a great deal.

It was many years ago that I first worked together with Peter on hearing voices and paranoia. He was hindered by both experiences. These experiences then get given a formal psychiatric diagnosis; the voice hearer is now seen as being 'mentally ill' within mainstream psychiatric practice.

However, more people are beginning to understand that the paranoia has its own background and can be explained by one or more traumatic life experiences. This was the case with Peter's paranoia. That was the reason why Peter proceeded in studying the paranoia phenomena and I studied together with Sandra Escher and a group of people the hearing voices experience. Paranoia and hearing voices are quite different phenomena; they can be related to each other, or they can be totally different as far as their history is concerned.

When studying paranoia Peter discovered with the help of different people the variation of life events that can precede the development of paranoid thoughts. Several of them have written about their experiences and these experiences are included in this book. There are some quite different background possibilities leading to the development of paranoia. In this book Patients as well as non-Patients have written about their experiences which might be interpreted as the cause of their paranoia. Immense traumatic

experiences during their younger years of life are mostly at the bottom of their developing paranoia. These are often the reflections of situations in which they felt anxiety and did not feel safe anymore.

For most people who can cope with their thoughts of paranoia, they often find a supportive person who is able to help them rationalize their paranoid thoughts. These are often those closest to them, partners, friends or sympathetic professionals who helps them give their life and paranoid experiences meaning.

Peter explains the process of developing paranoia. He tells us that paranoia fluctuates with the life circumstances of the person. He shows us the phases in a process interacting with problems in daily life. These can be different in different phases. In his case it was the mental abuse by a babysitter when he was quite young and later in life money problems had the same effect because there was nobody to support him. This changed when he met his current partner who was extremely supportive and helped him cope with his difficulties. In more stories in this book, we see the importance of love and supportive relationships.

In learning to cope with paranoia it is important to know a person's life story. You will have to look at paranoia as a kind of story, he explains. You will have to discuss the life history from the beginning and that is already quite difficult because people who experience awful traumatic experiences often do not want to revisit them. *Talking about trauma can be traumatic*. In this book, various contributors discuss techniques to help us make sense of paranoia. It discusses ways to help people to function when the traumatic experiences are too intruding. In essence it implores us to recognise that there is a constant need to recognise the relationship between current trauma and present and past difficulties.

Marius Romme

INTRODUCTION

PETER BULLIMORE, IAN WARWICK
AND KENNETH MCLAUGHLIN

In traditional psychiatry extreme paranoia is usually considered to be a symptom of psychosis. Diagnoses include paranoid schizophrenia, delusional disorder (persecutory type) or paranoid personality disorder (PPD). Paranoia can also be regarded as a symptom of depression and a feature of dementia (DSM–5; American Psychiatric Association, 2013)[1]. The aim of treatment is generally to reduce distress by eliminating the beliefs (usually through the use of medication) and seeks to make the person more 'rational'. It is no surprise then that mainstream psychiatric texts and many mental health professionals often start with theoretical explanations for people's experiences of mental distress. Whilst medical explanations predominate, political, psychological and sociological explanations are also common, and all are often interwoven within a biopsychosocial model of mental distress. The direct experiences and personal narratives of the sufferers themselves are then used as evidence to substantiate pre-existing concepts.

This book takes a radically different approach. Here, the personal narratives[1] of sufferers are prioritised and then the prevailing theoretical frameworks are examined to see if they fit with the sufferers' lifeworld rather than the other way round. Our conclusion is that seen from this perspective they are inadequate, and we therefore propose new alternatives to both the conceptualisation of paranoia and ways to intervene to alleviate the suffering of those experiences such as distressing beliefs.

What the contributors to this book have in common is their direct experience of paranoia, either through a lived experience perspective, providing professional support or developing new theoretical explanations to help us understand both the influences on, and experience of, paranoia.

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[1] American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

We therefore repost the question to ask whether psychiatric theory fits with personal narratives rather than the more common, and flawed, approach that foregrounds psychiatric explanations and then fits personal experience into such pre-existing medical categories.

The contributors to this book come from a range of positions, from those who have used, or been forced to use, psychiatric services, often referred to as 'experts by experience'[2] as opposed to the mainstream viewpoint that sees the professionals as the experts, diagnosing and positing a care plan, with the patient as a passive object to the mental health professional. Other contributors include psychiatrists, psychologists and social workers who also see the need to improve practice by listening to and working with the personal narratives of those with whom they are working. A variety of therapeutic techniques from practitioners are also highlighted which give us a useful catalogue of strategies to improve the lives of those who approach them for help.

As such, this book is directed at psychiatrists, psychologists, psychotherapists, nurses, social workers, occupational therapists, support workers, peer specialists, students and people who have had difficulties with paranoia and unusual beliefs.

The book is divided into three main sections:

Section one has a foreword form Professor Marius Romme, whose work with voice hearers has been immensely useful in improving our understanding of the phenomenon and the importance of engaging with voice hearers. Following this introduction, Peter Bullimore's chapter discusses the established view of paranoia versus the phases experienced.

Section two's focus is on the personal narratives of people who have experienced severe trauma and paranoia. They can be a painful read as they detail some horrific events in their lives. For some the resultant trauma saw them sectioned under the Mental Health Act and taken to hospital against their will, something that is often necessary but nonetheless traumatic for those subject to it. Some contributors did not require such drastic action and they detail how they coped with their paranoia in such a way that this was

[2] The personal accounts have not been adapted to fit any theories. Apart from a little proofreading assistance, the editors have left the personal accounts entirely as we received them and included them unabridged. Where necessary some names have been anonymised.

not necessary. The experiences of family members are detailed in the final chapter of this section of the book.

Section three discusses theoretical and practical approaches to managing paranoia from a variety of perspectives, from a critique of mainstream psychiatry to the use of Cognitive Behaviour Therapy, the benefits of co-construction work and other strategies to help people cope with trauma and paranoia.

We finish by summarising the key points of the book and what we hope the reader will have gained from it.

As the subtitle to this book suggests it combines the personal, professional and theoretical in relation to understanding, coping with and working with paranoia. However, these are all intertwined and so each appears within many of the chapters. It is not possible to conceptualise paranoia through a single lens. That was the problem with mainstream psychiatry which often attempted to reduce the human experience to one word ‘schizophrenia’.

Given such a variety of views the reader will see that there is often disagreement over the meaning of trauma and paranoia and over the best approach to working with those affected by it. As editors we often do not agree so it is no surprise that our contributors favour some perspectives over others, but what we and all the contributors share is the importance of listening to the personal narrative of those experiencing paranoia.

CHAPTER ONE

THE ESTABLISHED VIEW OF PARANOIA VERSUS THE PHASES EXPERIENCED

PETER BULLIMORE

Introduction

This chapter explores the established view of paranoia and compares it to the *Three Phases of Paranoia* approach, highlighting the significant differences between them. It looks at how by accepting someone's alternative realities and seeing their experiences through their eyes we can decode what can often be seen as unusual beliefs and make sense of them from their perspective. The Three Phases approach highlights the importance of identifying triggers and early warning signs, recognising them, rationalising them and learning to cope with them.

There follows an exploration of the development of paranoia, how it can be related to past events in a person's life and how to make sense of it by understanding the person's frame of reference. It looks at strategies to cope with fear and how to help a person learn from others with similar experiences so they can move on with their life.

In the final section the focus is on the role of trauma in the life of a person who experiences paranoia. It explores how trauma can be identified, how it can be overcome in a holistic way and how this can help the person develop emotionally and gain control of the existing fears that are often based in childhood events.

Within the established view of paranoia, paranoia is an unfounded or exaggerated distrust of others, sometimes reaching delusional proportions. Paranoid individuals constantly suspect the motives of those around them, and believe that certain individuals, or people in general are 'out to get them'. The definition describes the outcome quite well although from the

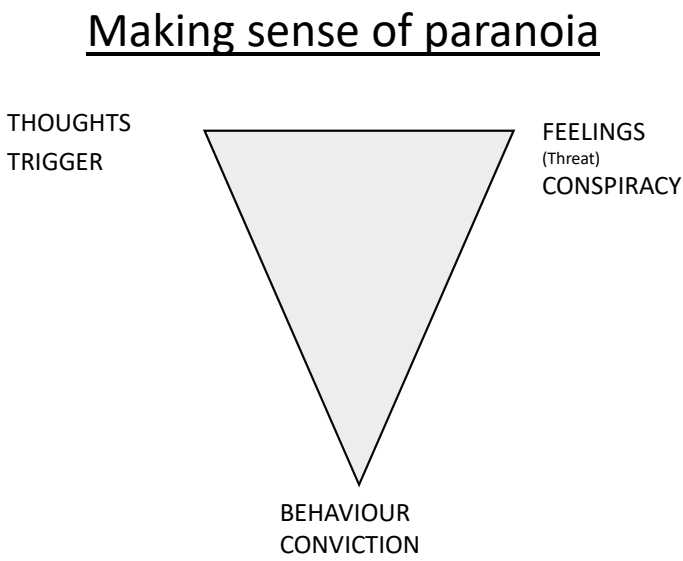
point of view of the outsider. From the insider point of view there are several differences:

1. Paranoia is a process with phases of development.

2. There is an interaction between the life situation or events and the phases in a process.

This definition suggests a continuum of suspiciousness. My own story, and that of others that I met in the paranoia support group (which I started in Sheffield), shows that paranoia fluctuates with the life circumstances of the person. We can speak of phases in a process interacting with problems in daily life, often leading to the paranoia becoming emotionally overwhelming leading to very threatening and real effects on the person. The figure below shows the interaction process.

Fig. 1.



In my story, the trigger thought time and again from the start of the process is: Nobody is helping, and everybody knows my (or our) problem. In my childhood, the mental abuse I suffered from a babysitter provoked major anxiety; I felt threatened and was made powerless. In later life, money

problems had a similar effect when lack of money made me powerless, and I could not solve this problem by working hard and I again felt threatened by a demanding woman; this time it was someone important in my life.

The next steps in the process are the feelings of anxiety and being threatened, without having the possibility to change or solve the problem. These feelings provoked within me the idea of a conspiracy: *The whole world is plotting against me.*

The following step in the process is my behaviour. I start to isolate myself. As a child I did not go to school anymore as I thought teachers were part of the plot to hurt me. As an adult I stayed home and shut myself up in the kitchen of my apartment for three months. Then the conspiracy idea becomes a conviction people are out to hurt me.

It is not necessary that all steps follow each other every time. In my case I once found, or attempted, another solution and went into organised crime where being paranoid was useful in carrying out the crime and in the art of avoiding being caught. On another occasion I found a better job that solved my financial problems.

In mental health care or psychiatry, a paranoia delusion is defined as an irrational, yet unshakable belief that someone is plotting against one or doing someone harm.[1] This is mainly an outsider's point of view, whereas when we go a step further and analyse the relationship with the person's life story or actual circumstances in life we observe that people build constructs to keep themselves safe. When we decode beliefs, they are not irrational or unshakable in terms of the life history. It therefore is important to interview a person about their paranoia/beliefs and for that we have developed an interview schedule.

How can we support a person with disruptive paranoia?

Paranoia varies in the degree to which it is present and the disruption it causes. To help people with their paranoia, one needs to have knowledge about the person's background and experiences in life.

[1] https://medical-dictionary.thefreedictionary.com/paranoia

Identifying the person's alarm system

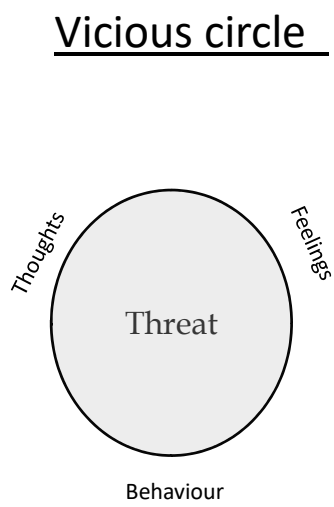
Identifying a person's alarm system is very important as the alarm system precedes the trigger thought. When the alarm system is set off, it triggers the thoughts that then set off the cycle of phases, trigger, conspiracy and conviction. For example, my alarm system would be females in authority. If I felt threatened by a female authority figure, it would trigger my thoughts. This would lead me to think that I am going to be controlled again and this would make me feel like I was the child who had his control taken away. It is also important to remember that these phases can fluctuate as you can have a feeling before you have a thought. How we feel at the time can activate our thoughts so it can go both ways; thoughts can activate feelings, but feelings can activate thoughts.

The thoughts being triggered are the main problem

Why should a comment or look create so much distrust in the person? If we understand what triggers the thoughts, we can often understand the conviction that leads to the behaviour. It is important to remember that the behaviour is secondary. We have to understand why someone behaves in the way that they do, or we will not understand the person's actions; look at paranoia as a kind of story.

- What is happening in the person's life?
- What does this mean to them?
- It is important to keep the belief safe.
- Help them try to make sense of a confusing reality.
- What is their history?
- How have they got to their present situation?
- What brought them to mental health services?
- How does the present relate to the past and the past to the present?

Fig. 2.



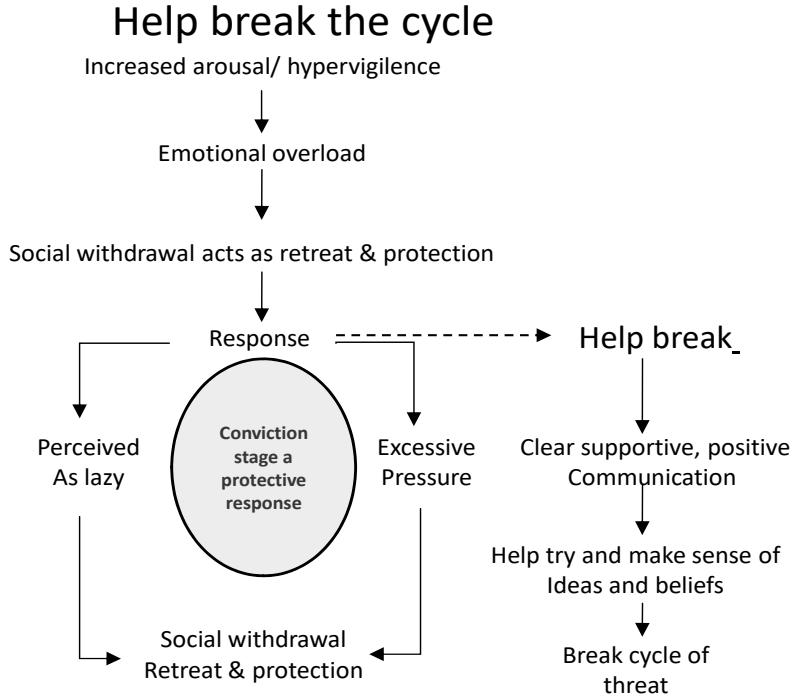
The vicious circle

When working with people use this example:

Conviction	→	Explore	→	Story (What is happening now?)
Conspiracy	→	Explore	→	History (How have you got here?)
Trigger	→	Explore	→	Past/Present

(Determine the relationship between past & present experiences)

Fig. 3.



Identifying Triggers

In learning about how the process of paranoia develops (Fig 3.) it is helpful to know about the alarm system that might provoke and trigger the thoughts. This could be situations and emotions that might lead to activation of the vulnerable person's difficult thoughts.

Some of these are:

- Increased responsibility
- Too much pressure
- Lack of sleep
- Fear of failure
- Inability to say "NO"

- Alcohol
- Strangers
- Animals
- People in authority
- People shouting
- Coincidences
- Public transport

Warning signs

Another point to attend to is warning signs; these are signs that indicate the paranoia process is in danger of developing and of the possibility of the person feeling that they could lose control.

Warning signs can be:

- Racing thoughts
- Seeing things
- Increase in a person's voices or their negativity
- Not making time to eat
- Altered sleep pattern
- Increasing isolation
- Drinking more alcohol
- Taking more drugs (either legal or illegal)
- Spending more time around others

These warning signs are not specific to people who experience paranoia but can also be warning signs of a manic episode developing, or if a person hears voices their voices could be turning nasty or other expressions of a decline in their well-being.

When does paranoia become a disorder?

John is a traveller. He does not register for tax, health, or other benefits as he believes it is the main way the state keeps its eye upon you. He refuses to let his children attend school and is very reluctant to take them to hospitals, if he does, he will not give names or gives false names.

Is he ill? Why?/Why not?

It is not a disorder because it does not affect his social functioning.

But he does have a paranoid personality.

Marion says her psychiatrist is an alien who wants to kidnap her and perform experiments upon her. She gets angry every time he tries to speak with her and refuses to be left alone with him. She has told him that if he comes near her again that she will defend herself and is learning self-defence in case she meets him of any of his fellow aliens.

Is she ill? Why?/ Why not?

What could be creating her paranoia?

She was taken from home forcibly medicated and given Electroconvulsive Therapy (ECT), so she sees it as being experimented on.

Her paranoia is based on some reality.

Accepting Alternative Realities

Easy, simple practical ways of coping

Working within a person's own reality is straightforward and can be used by anyone; special training is not required. The strategies are simple to use and successfully used by nurses, social workers, occupational therapists, support workers, psychologists, relatives of people with unusual beliefs, as well as those using them as self-help. Attempting to change someone's unshared or unusual beliefs can result in emotional distress arising from the experience of not being believed.

Imagine you were being discriminated against because of your race or gender and when you complained about it no-one believed you, but instead told you that you were misinterpreting things. It is likely that you would feel a range of unpleasant emotions such as depression, feelings of being judged or anger. Belief modification techniques attempts to suggest or convince people that their unusual beliefs are wrong. This can cause these same feelings and so result in alienating the person with unusual beliefs. Here are some examples of what people say and how we can decode them, offering alternative explanations in order to understand the beliefs.

- I am an alien.
  Meaning: I feel like an alien, I do not fit into society.
- I am being poisoned.
  Meaning: I don't feel like I can trust people right now, medication is making me feel sick.
- I am a prophet.
  Meaning: I have to be a prophet, or I am just a crazy person.
- Someone is watching me.
  Meaning: Why am I being observed on the ward?
- There is a secret army out to get me.
  Meaning: People/family are keeping secrets about my problems.
- Vampires attack me.
  Meaning: Why do they take my blood every month? The person is on Clozaril medication.
- There are different doors to a parallel universe.
  Meaning: The person is dissociating.
- My father is an emperor.
  Meaning: As an emperor's son I am special and will be noticed.
- I am a fox.
  Meaning: I have to be hypervigilant and guard myself against danger.
- Hitler is alive.
  Meaning: There is a dictator in my life.
- I am a philosopher.
  Meaning: I am trying to make sense of this confusing reality.

When working with someone's beliefs or paranoia it is important to remember that there is always a seed of truth in the belief. It could be completely true. Only seeing their beliefs through your own eyes means you may not understand them from their perspective. You have to see the beliefs through the eyes of the person who is experiencing them to make sense of them.

How beliefs are maintained

- Avoidance
- Lack of knowledge about anxiety or social skills (i.e. no reality testing)
- Unsuccessful strategies that reinforce beliefs
- Lack of communication

Intervention

- Form a therapeutic alliance
- Be non-confrontational
- Remember the protective function the beliefs may serve and help the person with their self esteem

Informal questions

- How did you cope?
- What did you do?
- When was the last time you noticed yourself being monitored?
- What did it feel like?

Exploratory questions

- Could anything bad happen to you if you were monitored?
- Have you heard of this happening to anyone else?
- What would it mean if …..happened?
- How small would a camera need to be?
- What led the police to be interested in you?
- How much would this surveillance cost?

Dealing with intrusive thoughts

How can the TV or radio refer to me?

Date / time	Who referred to you?	What did they say?	What do you think it meant?	What else could have been meant?

Thought reading or interference with thoughts

Date/time	Who seemed to read your thoughts?	What were you thinking at the time?	What made you think that they had read your thoughts?	Were there any other possible explanations?

Critical thoughts

If your thoughts are critical and saying nasty things to you, ask them "Why am l all these things?" If it cannot justify what is says why believe it? This offers an opportunity to challenge and question such thoughts.

The importance of language

When working with someone's experiences the language that we use is very important.

Never use the word 'believe'. This says to the person "you believe it" "but I don't". We can ask what they feel that their beliefs are, or what they describe their beliefs as. It has the same outcome, but it is not dismissive.

Do not collude with someone's beliefs if you don't understand them, you could get drawn into a world that you don't understand.

Do not dismiss their beliefs. You can say "I don't share your beliefs, but what do they mean to you?" This is what is called 'the fit'; the person is trying to make sense of a confusing reality.

Important therapeutic factors to consider

Developing an explanation of their experiences allows someone to make sense of them and does not unduly distress them.

Being in contact with a community who share these meanings e.g. spiritualist churches, paranoia and unusual beliefs groups.

Engaging in certain group related practices e.g. meditation, political action.

Conclusion: Take the power back

Many overwhelming/paranoid beliefs hinge on the person feeling out of control of themselves or their lives. The beliefs themselves are not the problem. The problem is the fear and the powerlessness that the person experiences.

Fear and powerlessness can block recovery and keep people stuck in cycles of distress.

Finding some power within the belief system can be a great leap towards recovery.

Never attack belief systems. They are important.

SECTION TWO

CHAPTER TWO

ACCEPTING PARANOIA

SHAUN HUNT

Introduction

Paranoia is often defined as an unfounded or exaggerated distrust of people and their intentions. It is also thought of as symptom of an underlying illness within the person experiencing it, but is it as simplistic as that? We tend to just dismiss a person's fears as unfounded and meaningless. However, all belief systems are rooted in truth (no matter how outrageous they may appear to people from the outside looking in).

I intend to use my own personal experiences of paranoia in this chapter to show that people can live fruitful and meaningful lives despite the presence of difficult thoughts and feelings. When we begin to understand a complex belief system rather than just dismiss it, it opens up the opportunity to live with these fears rather than be dominated by them. I want to start with my childhood experiences. This is the context of my life that is often missed during mental health assessments. If you take my so called 'symptoms' as a standalone presentation without the context applied, then they do not make any sense. Conversely, when the context is added it, all begins to make perfect sense.

The context

My story began way back in the early 1970s. After a relatively uneventful early childhood I moved in to live with my grandfather when I was 8 years old. There was no grandmother around as she had died long before I was born, so it was just me and him. My grandfather was a huge man in stature, so strong that the locals used to call him 'Hercules'. Despite his physical size though, he was a very warm, loving and caring man.

The reason he took me to live with him was that he had found out that I had been sexually abused by my own father. It was very shortly after arriving at my grandfather's that I began to hear a voice, a very warm friendly voice. The voice sounded a lot like my grandfather, but I knew it wasn't him. Around the same time, I developed a strange sensation that someone was watching me, everywhere I went and during everything I did, someone was always watching me. Looking back, it could be argued that this was when the paranoia began. However, I was not frightened by the sense of being watched, in fact it was the complete opposite. I interpreted the feeling of being watched as if I had a sort of guardian angel watching over me to keep me safe. This feeling of being watched has never left me, the only thing that changes is the way that I interpret it. As a young child living with my grandfather, I always felt safe. I could hear a voice that sounded just like him, I had a guardian angel watching over me and it felt that my life was already planned out for me (in a positive way).

Unfortunately, when I reached the age of 11, things changed quite dramatically for me. My Grandfather became physically unwell after suffering a heart attack. It became obvious that an old man looking after a young child like me was not beneficial for his health and I was returned to the family home. To add further context to the situation at this time, I had an older brother and two younger sisters; they had always stayed together as a family unit. My biological father had left, and my mother had remarried so I now had a stepfather. My Grandfather and I lived in a small town around 25 kilometres away from the family home, not a huge distance but we lived in completely different towns.

After moving in with the family, I very quickly became a target for local bullies both in the streets and in school. I was the 'new kid' in the area. I had no friends, nor did I have any allies. I was physically beaten on a regular basis by local children, but despite the bruises and cuts it was the emotional abuse that had the biggest impact on me. For example, I was always the last picked in school sports teams; no one would ever talk to me other than to insult me. I am sure most people will remember back to their own school days and picture a child walking around the edge of the school yard all alone. That was me. Compounding the regular beatings that I received from the bullies was the fact that my stepfather was incredibly violent towards me at home. He would punch me, kick me, stamp on me, and even come home drunk and drag me out of bed to beat me. It got to the stage where I was constantly covered in bruises, and I was not safe at home or in the streets.

Despite everything, the one thing that I could never understand was why was it only me? My brother and sisters were never hurt, neither sexually, physically nor emotionally; it was only ever me. I would never want any harm to come to any of my siblings but if it had been happening to them too it would have made more sense, but it did not; it was only ever me. My mother just let these things happen; she never stepped in to stop any of the abuses. It was as if she had only three children and I was just a stranger who happened to now live in their home. Looking back, I can see that my brain began to protect me. When I was beaten I no longer felt any physical pain, it was as if I just floated away when people were hurting me and it was happening to someone else.

I don't believe that children (and adults) are always credited with the incredible resilience they have within. I was in constant fear of being assaulted both at home and in the streets. I needed to find a place of safety, and I did. I found a place that seemed like it was 100 kilometres away. There were open fields, forests and lakes. It was like I had walked to a new country. The truth is my place of safety was probably a short walk down a country lane. I began to spend as much time out there as I could and I can honestly say, during all the time that I spent out there I never saw another living person, so nobody hurt me anymore.

I had time to think out there, even as a child I tried to make sense of what was happening to me. Why was I so different to everyone else? I toyed with various ideas, from religion to demons. I had wondered if I was an alien? Had someone left me here by mistake and would they come back to collect me when they realised?

Even at the age of 11 and 12 I began to sleep rough in the forest for days on end. I made a shelter and would catch snakes and newts to sell to the pet shop in the town. People often ask me: how could a child feel safe sleeping in a forest? My answer is: it was a lot safer than what was outside; in there no-one would hurt me. I often used to think back and wonder: why did no-one notice? Now I ask myself: why did nobody do anything as someone must have noticed?

By now I had begun to hear more voices, but they were no longer as pleasant. The feeling of being watched was still there but it was no longer a guardian angel, it was something far more sinister.

At the age of 13 someone did finally notice, and they did something. I was taken away and placed in a children's home in the care of the local authority.