

Psychosis

Stories of Recovery and Hope

Note

Health and social care practice and knowledge are constantly changing and developing as new research and treatments, changes in procedures, drugs and equipment become available.

The authors, editor and publishers have, as far as is possible, taken care to confirm that the information complies with the latest standards of practice and legislation.

Psychosis

Stories of Recovery and Hope

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Guy's and St Thomas' Charity

Guy's and St Thomas' Charity is delighted to have supported this inspiring collection of personal narratives, highlighting the many different symptoms and roads to recovery experienced by people with psychosis.

The Charity has a track record of supporting initiatives to promote a better understanding of psychosis and encouraging early diagnosis, as well as more effective treatment and recovery. It is also keen to tackle the stigma and taboo associated with mental ill-health, through academic studies and training for professionals, as well as arts projects which challenge common misconceptions around the syndrome in the wider community.

Guy's and St Thomas' Charity supports initiatives that enable innovation, creativity and learning in the NHS, with a particular focus on improving health and wellbeing in Lambeth and Southwark. The Charity supports a wide range of activities and services to improve clinical care, pioneering innovations in diagnosis and the prevention of ill health. Cutting-edge research is brought together with the insights of staff working on the 'frontline' to better understand particular diseases and disorders and to test new approaches towards delivering services. An improved clinical outcome as well as a better experience for patients is at the heart of the Charity's ethos.

The Charity's history goes back many centuries to the re-establishment of St Thomas' Hospital by Edward VI following the Reformation in 1553 and the building of Guy's Hospital by Thomas Guy in 1721. The careful management of the Charity's funds and assets, together with ongoing donations and legacies, continue to enrich the work of the hospitals and associated healthcare organisations today.

Further details about the Charity's work can be found at:
www.gsttcharity.org.uk

Biographies

Hannah Cordle is an assistant psychologist for South London and Maudsley NHS Foundation Trust. She previously worked for ten years in journalism and public relations before completing a postgraduate diploma in psychology.

Jane Fradgley studied fashion design and worked as a designer for many years. More recently Jane has been developing her skills as a photographer and has exhibited her work in galleries around London and the South of England. Her portraits have appeared in several mental health journals. Working in the voluntary sector, Jane assists in facilitating art groups for vulnerable adults.

Dr Jerome Carson is a consultant clinical psychologist. Jerome works in a community mental health team in South West Lambeth, part of the South London and Maudsley NHS Foundation Trust. Since 2006, he has been wrestling with the concept of recovery and has been involved in a number of local initiatives. In addition Jerome is currently inspired by the concepts of positive psychology and wellbeing, though appreciates the difficulty of applying some of these ideas with people with more long term mental health problems.

Dr Frank Holloway has worked as a psychiatrist since 1979. He trained at Kings College Hospital, London and became a Consultant Adult Psychiatrist in 1987. He has been involved in the closure of a large mental hospital and in the development of innovative community-based mental health services in South London. He is a former Chair of the Faculty of Rehabilitation and Social Psychiatry of the Royal College of Psychiatrists. His research interests include psychiatric rehabilitation, psychiatric ethics, mental health law and how mental health services work. He is an Honorary Senior Lecturer in the Health Services and Population Research Department of the Institute of Psychiatry.

Paul Richards is manager of the print department at Southside Rehabilitation Association (SRA) Ltd, a charity in West Norwood that provides employment training to people with mental health problems. He has over 40 years experience of design, printing and layout, most recently specialising in publications relating to mental health.

Chapter 1

Introduction - Understanding the Journey

Hannah Cordle

The seeds of this project grew out of two recovery initiatives which took place at the South West Sector Community Mental Health Team in Streatham between 2008 and 2010. Firstly, Dr Jerome Carson and six service users produced a series of papers entitled *Recovery Heroes* on individuals whose journeys of recovery from mental illness could inspire other service users and professionals alike (Sen et al, 2009). Secondly, Jane Fradgley led the *Photographing Hope* project where six service users attempted to define their own meaning of the word 'hope' by taking and exhibiting a series of inspiring digital photographs. These projects used a unique partnership model between service users and mental health professionals which enabled people to take a lead role in their own recovery. I was fortunate enough to work on both projects which, thanks to the commitment of our service users, Dr Carson's enthusiasm and Jane Fradgley's artistic vision, were a great success.

During this time it became clear that there was scope for a larger piece of work that would develop some of the themes around recovery and hope that we had touched upon. These included identifying real-life role models for people with mental illness; demonstrating that recovery is a real possibility; and promoting hope as an important factor in recovery. Another significant issue was the need to raise the profile of recovery from psychosis in a similar way as has happened with bipolar disorder in recent years. The reason for this was encapsulated by one of the contributors to this book, consultant psychiatrist Dr Glenn Roberts, the lead on recovery for the Royal College of Psychiatrists, who said, "People with bipolar disorder often seem accepting or even helped by their diagnosis, join organisations like the Manic Depression Fellowship, read *Pendulum* magazine, are often positive about their medications, set up self-management groups or even whole approaches and often appear as contributors, colleagues and leaders in recovery contexts. Not so people with a schizophrenia diagnosis... who are underrepresented in collections of recovery stories or as collaborative leaders in recovery contexts," (Roberts, 2010). The need to create psychosis recovery

heroes is justified within the pages of this book, with only one person naming economist and Nobel laureate John Nash as an exemplar of recovery from schizophrenia. Although his story, depicted in the film *A Beautiful Mind*, is inspiring it could be seen as distant and unobtainable to many ordinary people. So Dr Carson conceived the idea for *Psychosis: Stories of Recovery and Hope*, with the aim of showing that there are many positive, inspiring and untold stories of people not just coping with schizophrenia and related disorders, but who are also making valued and valuable contributions to society. We were successful in securing the support of Guy's and St Thomas' Charity, an organisation which has done such a huge amount to promote mental health in South London, including funding our own *Photographing Hope* project. Dr Carson was to be the lead clinical consultant with Jane Fradgley as the main photographer and artistic director. The expertise and assistance of consultant psychiatrist Dr Frank Holloway, former clinical director of Croydon Integrated Adult Mental Health Services, and designer Paul Richards of the South London-based mental health charity SRA Ltd, was also enlisted. My task, as a former journalist now working as an assistant psychologist, was to work closely with each of the 14 contributors to produce the narratives that would form the backbone of the book.

This process involved conducting a two hour long semi-structured interview, either in person or on the telephone, with each contributor. The interviews followed a standard format, beginning with a brief introduction of the person's background; a description of their transition into psychosis and experiences of the mental health system; and ending with their thoughts on recovery and hope. This format was chosen because I felt it was important to strike a balance between allowing the contributors – some of whom had patchy and impressionistic recollections of their own experiences – the freedom to tell their story in their own way while producing a reader-friendly result. It would also achieve the aim of making the text as clear and accessible as possible for our most important target audiences, readers with psychosis and their carers. Each narrative was then written up using the same structure to ensure a consistency of style across the book. The interviews were designed to draw out but not exaggerate the clinical aspects of having psychosis such as symptoms, medication or hospitalisation in each narrative. The reason for this, also identified by Dr Glenn Roberts (see his chapter in this book), was to avoid dehumanising the individual and reducing them to a diagnosis. It was equally important to include information on the individual's process of recovery and their understanding of the concept of hope, which to my mind could be more beneficial to others who were seeking recovery themselves.

There was very little editorial interference needed from me in the crafting

of these narratives. Indeed, in some chapters, large sections of the text are almost direct reproductions of the interviews themselves. Where this was not the case, I needed simply to join the dots rather than paint an entire landscape. Although I have a background as a reporter, I deliberately avoided using the journalistic technique of looking for the sound bite, hook or angle to each story. These stories do not necessarily have the traditional beginning, middle or end but were allowed to flow naturally from the individual and take on a life of their own. This aimed to reflect how recovery is a work in progress rather than a finished product for many people (Ward, 2009).

Some of the contributors were experienced in telling their stories, while others were not, yet all described them better than any third party could have done. Perhaps recounting the story orally to a trained writer, rather than trying to write it down themselves, facilitated this process. The resulting narratives are a tribute to, in the words of Bose Dania (see her chapter in this book), the contributors' understanding of the journey which in itself is a signifier of recovery. Each contributor has something original and practical to say on recovery, be it the importance of spirituality, getting a job or maintaining their personal appearance, which can offer us new directions in the recovery debate. The narratives are complemented by Jane Fradgley's powerful black and white portraits, which capture the dignity and individuality of each contributor.

During the editorial process, I was struck by the willingness, openness and enthusiasm of each contributor to tell his or her story. This was despite the potential distress that could be experienced by recounting and reading back a story of, in some cases, a lifetime dominated by severe mental illness. The bravery this entailed was brought home when one contributor told me that he had to mentally prepare himself before reading back the first draft. But when I asked the contributors for some evaluative feedback, the beneficial value of telling and rereading their own narrative also became clear. Some were surprised at how confident and open they appear in the text; others found it a useful benchmark of their own recovery; one contributor hoped her story would help others with mental illness by raising awareness and charitable funds. The process demonstrated the importance of narrative and showed how it could successfully be developed in future as a therapeutic intervention, even led by writers and journalists rather than psychiatrists or psychologists. It also revealed a hunger from the service users themselves for more opportunity to produce narrative, with several contributors seeking to take the work further through either publishing their own memoirs or developing other autobiographical projects.