

Cambridge University Press & Assessment
978-1-911-62369-4 — Coping with Psychosis and Schizophrenia
Family Stories of Hope and Recovery
Edited by Juliana Onwumere , David Shiers OBE , Elizabeth Kuipers OBE
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COPING WITH PSYCHOSIS AND SCHIZOPHRENIA

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‘When feeling bewildered and alone, with a sense of responsibility for a much loved relative affected by psychosis, the testimonies of others with caring experiences can be a lifeline. Professionals and students will also deepen their understanding by learning from carers. The authors have assembled, in this slim volume, a richly varied selection of personal accounts of caring, which will prove an invaluable resource for anyone concerned with compassionate care.’

*Philippa Garety, Professor of Clinical Psychology,
King’s College London*

‘This excellent book brings together unique perspectives and insights from a variety of relatives and care-givers who share the experience of having a loved one with psychosis. It will help others to understand the associated struggles and some of the ways people have been able to cope with these challenges. It should inspire hope and action for families and professionals alike.’

*Anthony P. Morrison, Professor of Clinical Psychology,
University of Manchester*

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Coping with Psychosis and Schizophrenia

Family Stories of Hope and Recovery

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ELIZABETH KUIPERS OBE

King's College London



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Every effort has been made in preparing this book to provide accurate and up-to-date
information that is in accord with accepted standards and practice at the time of
publication. Although case histories are drawn from actual cases, every effort has been
made to disguise the identities of the individuals involved. Nevertheless, the authors,
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manufacturer of any drugs or equipment that they plan to use.

David Shiers is expert advisor to the National Institute for Health and Care Excellence
(NICE) centre for guidelines. The views expressed are those of the authors and not
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National Institute for Health and Care Research (NIHR).

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Can someone navigate please!

This journey is difficult to navigate

There is no roadmap

There is thick fog

The possibility of stumbling, inadvertently into the obstacles, barriers, and roadblocks?

Are there any directions from those with the lived experiences and or the experts with science behind them?

Me, in between, pushed, pulled, malleable and worn out . . . longing for navigation to support such a journey.

Agnes

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ABOUT THE AUTHORS

Dr Juliana Onwumere is a consultant clinical psychologist in the South London and Maudsley NHS Foundation Trust in London, and a Reader in clinical psychology in the Department of Psychology at the Institute of Psychiatry, Psychology and Neuroscience, King's College London, United Kingdom. A key component of her research and clinical work focuses on family-related issues in psychosis, including developing and evaluating support interventions for families and providing specialist family-focused training for healthcare staff. Juliana developed the first massive open online (global) course focused on information and support for those caring for people with psychosis and schizophrenia (www.futurelearn.com/courses/caring-psychosis-schizophrenia). She has authored several academic papers and book chapters on family-related issues in psychosis.

Dr David Shiers OBE was previously a general practitioner (GP) in Leek, North Staffordshire, UK. David has been campaigning for mental health care reform since the late 90s when his daughter was given a diagnosis of schizophrenia in her late teens. Derived from what he felt was lacking in his daughter's early experiences of care, David changed his career, leaving general practice to co-lead the UK's National Early Intervention in Psychosis Programme through the era of the National Service Framework. Now 'sort of retired', Shiers continues to challenge why people like his daughter should accept poor physical health. He has taken part in several relevant National Institute for Health and Care Excellence (NICE) guidelines and quality standards including, most recently, the NICE guideline on rehabilitation for adults with complex psychosis. He has also been a clinical advisor to the UK National Audits of Schizophrenia since 2011. David has been acknowledged by the Royal College of Psychiatrists with the President's medal in 2012,

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and as ‘Carer of the Year’ in 2015. He was awarded an OBE in 2016 for services to vulnerable people.

Elizabeth Kuipers OBE is Professor Emerita of Clinical Psychology at the Institute of Psychiatry, Psychology and Neuroscience, King’s College London and, until 2012, was an honorary consultant clinical psychologist in the South London and Maudsley NHS Foundation Trust. She was the Chair of the National Institute of Health and Care Excellence (NICE) psychosis and schizophrenia updated treatment guideline for England and Wales in 2014 and 2009. Elizabeth was head of the Psychology department at King’s College London from 2006 to 2012 and a founding director of the PICuP clinic (Psychological Interventions Clinic for Outpatients with Psychosis) at the South London and Maudsley NHS Foundation Trust. Her research interests are in developing and understanding interventions in psychosis, family interventions and individual cognitive behavioural therapy (CBT). Elizabeth has authored and co-authored more than 400 articles, book chapters and books, and has more than 40,000 citations for her work. She has led large-scale, randomised controlled trials investigating the efficacy of CBT and family interventions for psychosis. She is a National Institute of Health Research (NIHR) Senior Investigator Emerita. In 2013, she received a Women in Science and Engineering (WISE) lifetime achievement award as well as a lifetime achievement award from the Professional Practice Board of the British Psychological Society. In 2018, as part of the New Year Honours List, Elizabeth was awarded an OBE for services to psychosis research, treatment and care.

PREFACE

The families and informal support networks of people living with a psychotic disorder are not necessarily blood relatives, but are commonly close relatives, namely parents, partners, siblings, or young or adult children. They are typically and collectively referred to as either *informal carers*, *carers*, *caregivers*, *relatives* or *families*. These are generic terms employed to denote the fact that they are providing support and care, but not in a professional or paid capacity. Further, the term ‘carer’ (and all its variations) is not universally defined, or always readily accepted or used by those in a caregiving role or by care recipients. The common course of a psychotic disorder, with its typical relapsing and remitting pattern, often means the carer role will be a long-term and, for some, a lifelong commitment.

The important role carers can play in facilitating better health and social outcomes for their relatives living with psychosis is widely acknowledged, including amongst people living with psychosis (sometimes referred to as service users), and by health services and staff. The role involves varied behaviours, including creating social environments to provide practical support, encourage recovery efforts and build confidence. Carers can be instrumental in accessing relevant mental health services at first illness onset and during a crisis (Del Vecchio et al 2015), supporting service user engagement with services and treatments, and improving treatment outcomes (Garety et al 2008; Doyle et al 2014). Carers can also significantly reduce levels of relapse and the number and length of psychiatric hospital admissions (Norman et al 2005). The social networks for many people living with psychosis will include a greater proportion of carers (e.g., Palumbo et al 2015). Evidence indicates that life expectancy rates can be significantly higher in people living with psychosis with carers compared to those without a carer (Schofield et al 2001; Revier et al 2015). In addition, the estimated cost savings from carers to national budgets are substantial, exceeding one billion pounds per annum (e.g., The Schizophrenia Commission 2012). Evidence of

their importance is further reflected across a broad range of treatment guidelines and recommendations for psychotic disorders (e.g., NICE 2014) and health and social care policies.

While carer experiences are highly subjective, almost all will assume their role with minimal or no time to prepare and without a manual or template on what one should do for the best for their relative, for themselves and for key others in their network (Kuipers 1992). A caregiving role in psychosis and doing things that are seemingly helpful for the service user and/or the carer can be largely based on trial and error, persistence, endurance, resilience, good fortune and the support and understanding from others. Informal caregiving roles are characterised by several experiences and emotional reactions that can present in one sitting or fluctuate, in parallel or independently, with the illness course. We know that many carers report high levels of psychological distress and poorer levels of positive wellbeing when compared to the general population (Gupta et al 2015a; Sin et al 2021). Further, psychological distress levels are particularly raised during the first illness onset, at times of relapse and crises, and during a psychiatric hospital admission, particularly if it was an involuntary admission (Kuipers et al 2010). Based on World Health Survey data from 48 countries, carers are at a higher risk for experiencing psychotic experiences (Koyanagi et al 2022). Approximately one third of carers experience clinical depression (Kuipers & Raune 2000; Prasad et al 2024). Reports of burnout and exhaustion (Onwumere et al 2018a; McKenna et al 2022), trauma (Kingston et al 2016), loss and grief (Patterson et al 2005), and social isolation (Hayes et al 2015) are not uncommon in carers in psychosis. Moreover, some carers might also be dealing with additional challenges in their role that include service user aggression and violence (Onwumere et al 2018b; Smith et al 2018; Onwumere et al 2019; Wildman et al 2023), and/or other types of anti-social, problematic and risky behaviours such as substance misuse (Winklbaur et al 2006). Carers are more likely to miss several days each year from their work and leave their paid roles because of caregiving responsibilities (Gupta et al 2015b; Mittendorfer-Rutz et al 2019).

Data from studies across the globe confirm that the challenging aspects of the caregiving role are evident across all types of carers,

including spouses and parents (Jungbauer & Angermeyer 2002); siblings (Bowman et al 2017); children (Cooklin 2018); carers from different ethnic, racial and cultural backgrounds (Jagannathan et al 2011; Alyafei et al 2021); and LGBTQ communities (Martin et al 2019, Worrell et al 2023). Not dissimilar to a person living with psychosis, carers can experience stigma, isolation and exclusion from others that might include acquaintances, but also close friends and relatives, and a generally felt sense of disempowerment (Adelman et al 2014). Mental health problems, particularly severe mental illnesses such as psychosis, are frequently associated with myths and inaccuracies about the groups affected and their underlying causes, which fuel stigma. Stigma and fear of negative judgement from others can make it harder for carers to seek support from others and share their experiences. Opportunities to speak with and be supported by other carers and supportive others can be important for promoting positive wellbeing and feeling valued.

It is important to note that for many carers, their experiences are not uniformly perceived as negative and can include positive, uplifting and transformative experiences, in parallel (Jordan et al 2018; Campos et al 2019). Such experiences are varied and idiosyncratic, but might include a sense of restored hope, pride, and improved self-worth and self-esteem which, in part, reflect their efforts in being able to offer support to their relative. The positive aspects might also include a new appreciation or deeper understanding of the difficulties faced by those living with disabilities or an improved relationship with the relative they support. Unfortunately, however, our understanding of these types of carer experiences and, more broadly, carer perspectives on what they find beneficial in their caregiving journeys has remained largely neglected in mainstream literature and/or limited to discussions in support groups and carer-only platforms. In our professional and personal lives, we have the privilege of meeting many carers from all walks of life. A key commonality is the uniqueness of their life experience and the areas they noted as having helped.

The next few chapters provide a series of first-hand accounts from carers where they candidly summarise some of their experiences and ideas on what has helped in their own coping efforts and personal recovery journeys. The accounts are written by a broad range of carers including

those who are parents, siblings and partners, and from varied socio-demographic backgrounds, including race and ethnicity. Some accounts describe experiences and mental health services from several years ago, while others capture more recent events and current service provision. There are accounts that coalesce around a specific event, while other accounts provide a more longer-term narrative. All accounts are offered as personal narratives. Thus, they do not seek to speak for or reflect the experiences of all carers. They are, and must be treated as, individual stories and perspectives on what has happened. Hence, there are and can be no right or wrong narratives, but only authentic accounts that provide an insight into the lived realities of being in a caregiving role in psychosis and factors identified as having been helpful. It is possible that you might be reading these accounts as someone in a caregiving role and are curious to see what other people have said. Likewise, you might be a healthcare professional (or student), service user or simply just someone interested in families and relationships. Irrespective of who you might be, these accounts offer a valuable insight into a much-neglected group. The accounts have been broadly organised around the type of caregiving relationship, for example, parental, sibling, partner caregivers. All authors are identified by the first name of their choice, which for some is their first name or a name that has meaning to them. Across all accounts, issues of confidentiality and anonymity were observed.

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