

## Who cares for the carers?

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'I'm in my late 50's and it is not what I expected to be happening to me at this point in my life. And I suffer huge guilt because as the mum of course it is all my fault. I know it isn't but anyway...'  
(Albert & Simpson, 2015, pp.6-7)

Psychosis is estimated to affect four in every thousand people in England alone every year (Kirkbride et al., 2012). However, this figure does not account for the hundreds of spouses, parents, friends and others whose lives are altered immeasurably when someone develops a severe mental health difficulty. Whilst this has always been the case, the move towards community care over recent decades, together with the increasing scarcity of resources in mental health services, means that we now rely more than ever on service users' families and friends to provide considerable amounts of unpaid care (Burns et al., 2012; Kuipers et al., 2010), often without adequately considering the impact of this on their wellbeing or providing appropriate support to enable them to feel confident in their caregiving role (Albert & Simpson, 2015).

Research into the impact of caregiving on the families and close friends of individuals with psychosis has developed over recent years. It is now well established that caregivers are in need of practical and psychological support (Kuipers, 2010; Roddy et al., 2014). Despite this, caregivers report that they

are rarely provided with advice and information, often feel overwhelmed by their caring duties and do not feel taken seriously by professionals (Albert & Simpson, 2015; Askey et al., 2009). They are faced with needing to navigate the complexities of mental health services, often not helped by poorly implemented confidentiality and information-sharing policies (Kuipers, 2010). Caregivers also play a key role in alerting professionals to mental state changes in the person they care for, and instigating medication reviews and inpatient admissions, often without their loved one's knowledge, or against their wishes, for which they may be blamed by the person they care for.

Kuipers (2010) argues that mental health services specialising in psychosis should be taking specific responsibility for the wellbeing of caregivers, alongside service users. Guidance published by the National Institute for Health and Care Excellence in 2014 recommends that psychosis teams should assess the needs of caregivers, jointly develop a care plan based on these needs, and provide information, support and an opportunity for caregivers to be included in decision making whenever possible (NICE, 2014). Whilst support for caregivers in other areas, such as dementia (Brodaty et al., 2003; Thompson et al., 2007), is well established, it remains relatively rare for psychological support to be offered to caregivers in psychosis services. Support offered by voluntary or charitable organisations, although valuable, lacks

integration with mental health services, and, therefore, the care of the service user, and is rarely psychosis-specific. Group interventions have been trialled in some psychosis services to address some of the psychological needs of caregivers; groups provide opportunities for peer support and the sharing of stories, together with the delivery of psychological strategies such as problem solving, goal setting and action planning, which can help to gradually rebalance caregivers' views about blame, causation, roles and responsibilities. This in turn can improve their relationships with the people they care for (Chien & Norman, 2009). Unfortunately these interventions are typically delivered within time-limited research projects, which do not generalise into routine, ongoing care.

In Lambeth and Southwark in south London we have been developing a new support service for caregivers of service users with established psychosis within community mental health teams. Over the last three years we have devised and adapted our service protocols and pathways, based on NICE guidance, emerging evidence (Roddy et al., 2014) and feedback from caregivers. Local NICE implementation funding has supported the appointment of one full-time psychology graduate in each borough, each covering four locality teams, each of which holds a caseload of 200-250 service users with psychosis. There is therefore a considerable workload and one of the most challenging aspects is the management of a large number of clients. Supervision and governance by senior clinical psychologists, and working as a cohesive and supportive team, have been essential.

Clinicians are able to suggest caregivers who may appreciate being contacted, or caregivers can self-refer. Since September 2013 we have been offering caregivers an assessment of their needs, followed by brief psychological interventions when appropriate. These focus on key areas such as psychoeducation around psychosis,

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treatment and management, improving communication, problem solving and crisis planning, in addition to signposting to community services addressing financial and social issues. Psychological interventions also address caregivers' own mental health needs and key emotional issues that impact on the caregiving relationship, most commonly grief, loss and guilt, which may lead to over-involvement and difficulty setting boundaries. Concerns raised by caregivers are always passed on, with caregivers' consent, to the relevant clinical team. There is also a support and information group programme to facilitate peer support.

Working with caregivers is a humbling, challenging and often frustrating experience. The cognitive model of caregiving in psychosis highlights the importance of caregivers' appraisals of and reactions to their role, which is something that has become apparent to me in my clinical work. For example, if a caregiver believes that they are the one to blame for their loved one developing psychosis, then they make it their life's work to protect them from any further harm, and experience guilt, loss and social isolation (Kuipers et al., 2010).

The largest group of caregivers we see is parents, sometimes of young adults but often of middle-aged people who have struggled with their mental health for decades, and been unable to live fully independently. These caregivers may be ambivalent about the offer of support, often reporting that it is 'too little too late' after a lifetime of caring. Parents have also told us that they often imagine the life that their child might have had, and mourn their lost opportunities. Others say that they worry as they get older about who will be there when they are no longer able to care or when they die.

These parental concerns have been highlighted in past literature (e.g. Askey et al., 2009; Chambers et al., 2001) and reflect the significance of the psychological impact of psychosis on service users' families. Furthermore, the understanding that caregivers have of the prognosis of psychosis has been shown to be related to their affect (Kuipers et al., 2007), indicating that offering balanced, accessible information to caregivers may be beneficial for their mental health.

Some caregivers we meet are greatly relieved to be offered their own support, attend well and really absorb information shared with them. They tend to make changes in their communication styles and the boundaries they set in response to our advice, and offer support to other caregivers in groups. They might remain in contact with the service and get in contact when further help is needed. Others may present to us in

great distress, needing an outlet for their grief and sadness. In line with past research we have found that many of the caregivers we see experience clinically significant symptoms of anxiety, depression and physical health problems (Hayes et al., 2015). Caregivers have often been through the same traumatic experiences as service users that are known to increase vulnerability to psychosis, such as migration, discrimination and exposure to, or experience of, abuse (e.g. Kirkbride et al., 2012). However, for caregivers, the focus on the individual with psychosis has often prevented them from seeking help for their own mental health needs, which may have been compounded by the traumas associated with supporting someone through episodes of psychosis. These may include dealing with the

police, the Mental Health Act and related legal processes while, until now, receiving little or no support with the distressing, frustrating and confusing nature of these experiences. Trauma survivors may also feel shame, layered on top of the stigma associated with having a family member with a mental health diagnosis (see Corrigan and Miller, 2004), and we need to work hard to provide a safe, non-judgemental space for caregivers to tell their stories.

Other caregivers come to us wanting something to be done. They do not necessarily consider themselves as needing support, but may ask for more interventions for service users, want explanations for why certain decisions have been made, or just want to express dissatisfaction with services more generally. A common question asked by some caregivers is 'Why can't they be made to do it?' – 'it' may be to take their medication, or attend psychological therapy or vocational activities. When it becomes apparent that we, and indeed the care team, cannot do this, these caregivers might disengage.

Caregivers usually accept our support initially, although rates of disengagement and non-attendance are high, perhaps due to caregivers' busy lives, their lack of belief that things could get better or the low priority they give to their own needs (Hayes et al., 2015). This does not detract from the value of being offered support, even if it is not fully accepted. Although we may not be able to change the situations that caregivers face, we can do our very best to apply our knowledge of mental health, together with empathy, validation and respect, to ensure that they no longer feel alone in their struggle.



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