

# Supporting the wellbeing of carers of people with complex mental health needs

## The issue

Carers who support family members or friends with complex mental health needs may contact social care for support. They might also be referred for a Carer's Assessment by social care practitioners, or by friends or family because of concerns about their wellbeing or the wellbeing of the person they are caring for. Carers are entitled to an assessment of their needs, but it can be difficult for social care staff to know how best to support their wellbeing.

## What we wanted to find out

What works best to improve the wellbeing of carers of people with complex mental health needs?

## What we did

We searched PsycInfo and PubMed for relevant systematic reviews published after 2013. We looked for reviews evaluating support offered to adults caring for other adults with complex mental health needs that arise from conditions such as psychosis, schizophrenia or emotional intensity disorder. We also looked for guidance produced by the National Institute for Health and Care Excellence (NICE) on this topic.

We wanted to know what might help improve carer wellbeing. We looked for evidence of what improved carers' quality of life, or reduced feelings of 'burden', anxiety, stress, or a sense of being unable to cope.

## What we found

We found nine systematic reviews.<sup>1-7</sup> Most focused on carers of people with named mental health conditions. Two further reviews looked at support delivered using digital technology.<sup>8,9</sup> We also found NICE guidance that included recommendations on supporting carers.<sup>10,11</sup>

The kinds of support evaluated vary. 'Psychoeducation' is the most common approach. This combines information, education and discussion about mental illness with activities and resources to help carers cope and problem-solve.<sup>11</sup> The approach is based on the idea that understanding a problem can help a person manage it better. Psychoeducation may be offered alone, or alongside another therapeutic approach. In the research we looked at, it was usually facilitated by someone with expertise in mental health.

Studies also evaluated other psychological therapies, particularly those based on Cognitive Behavioural Therapy (CBT)<sup>1,3,5,8</sup> or Dialectical Behaviour Therapy (DBT).<sup>2,3</sup> These often involved the person being cared for. Some reviews considered the effectiveness of activities such as mindfulness or yoga,<sup>8</sup> and support groups.<sup>7</sup>

Studies often looked at interventions aimed at carers of people with specific diagnoses, and this makes it difficult to know whether their findings apply more widely.

## What the evidence suggests

For carers of people with complex mental health needs, programmes that include psychoeducation can help to reduce the feelings of burden<sup>1,2,4,6,8</sup> and psychological distress<sup>2,4,6</sup>

that can be associated with caregiving. They can also improve different aspects of quality of life and feelings of wellbeing.<sup>6,7</sup> Carers may also benefit in similar ways from access to psychological therapy such as CBT or DBT.<sup>2,3</sup>

Where studies have measured it, research suggests that providing psychoeducation can help carers to better understand the needs and behaviours of the person they are caring for.<sup>1,2,3,4,6,8</sup> Alongside coping strategies, this is thought to help carers better manage their caregiving role.

Psychoeducation and therapeutic programmes vary in terms of how they are delivered and who and what is involved. From the research we looked at, it is not clear exactly what approach is best, how long a programme should last, or how long its beneficial effects might be.

It is possible to provide psychological support for carers using digital technology.<sup>9</sup> Some carers valued opportunities for peer discussion and mutual support provided in this way, but accessing support like this is not for everyone and it made some carers feel more isolated.<sup>8,9</sup>

Importantly, the evidence we looked at included little about how adult social care staff can themselves best support carers of people with complex mental health needs, or about how to best integrate mental health and social care services to help support carers' wellbeing.

### What the guidance suggests

Trusting relationships with professionals can help carers feel less isolated. When carers feel informed, understood, and supported, they feel less anxiety and stress. Peer support groups are valued by carers and can help them navigate services.<sup>10</sup> Carers of people with psychosis and schizophrenia should be offered a carer-focused education and support programme.<sup>11</sup>

### What this means for practice

Carers would benefit from carer-focused education and support programmes that include information about conditions, their treatment and management, and opportunities for mutual support and discussion. Carers may need practical support, including respite care, if they are to benefit fully from support services available to them.

Social care commissioners should work alongside secondary mental health service colleagues to ensure that therapeutic programmes, including psychoeducation, are available to carers, and that referral pathways are in place to enable access to them.

When conducting Care Act assessments, social care practitioners and Care Coordinators in integrated teams should understand the importance of supporting carers and of signposting them to services. Best practice examples such as the Triangle of Care (see Further Information) may help practitioners manage the relationship between carers, people accessing care and support and themselves.

In addition, it is important to recognise that guidance and recommendations about supporting carers of people with other physical or mental health conditions may apply equally to carers of people with complex mental health needs.

### Quality and completeness of the evidence

There is limited evidence around how adult social care staff can best support the wellbeing of carers of people with complex mental health needs.

Many of the studies we included looked at very different kinds of support. Studies sometimes involved small numbers and used different measures to assess outcomes for carers. They did not always report results clearly. While there is a significant amount of research available, we can only be moderately confident in the findings we report in this briefing. In particular, the evidence on online or digital interventions is based on a small number of studies and should be treated with caution.

## Further reading

- The Triangle of Care was developed by carers for The Carers Trust to support and sustain carer wellbeing: <https://carers.org/triangle-of-care/the-triangle-of-care>
- Rethink Mental Illness support people affected by mental illness, providing programmes and support groups for carers: <https://www.rethink.org/>
- NICE Quick guide to supporting people who provide unpaid care for adults with health and social care needs: <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/supporting-people-who-provide-unpaid-care-for-adults-with-health-or-social-care-needs>
- RiPFA Social Work Practice with Adults: <https://carers.ripfa.org.uk/>

## Contacts for further information

Kath Leman (North Somerset Council Evidence Champion): [kath.leman@n-somerset.gov.uk](mailto:kath.leman@n-somerset.gov.uk)

Karen Gray (North Somerset Council Researcher in Residence): [Karen.gray@bristol.ac.uk](mailto:Karen.gray@bristol.ac.uk)

## Definitions

*Cognitive Behavioural Therapy (CBT)* is a structured therapeutic intervention focusing on how thoughts, beliefs, attitudes, feelings and behaviour interact. Delivered to an individual or in a group by a practitioner with therapy-specific training, it teaches coping skills to help people deal with life differently.

*Dialectical Behaviour Therapy (DBT)* is based on CBT but is specially adapted for people who feel emotions very intensely. 'Dialectical' means trying to understand how two things that seem opposite could both be true.

## References

- <sup>1</sup> Baruch, E. et al. (2018) Psychological interventions for caregivers of people with bipolar disorder: a systematic review and meta-analysis, *Journal of Affective Disorders*, 236, 187-198
- <sup>2</sup> Guillen, V. et al. (2021) Interventions for family members and carers of patients with borderline personality disorder: a systematic review, *Family Process*, 60: 134-144
- <sup>3</sup> Sutherland, R. et al. (2020) Support, interventions and outcomes for families/carers of people with borderline personality disorder: a systematic review, *Personality and Mental Health*, 14: 199-214
- <sup>4</sup> Sin, J. et al. (2017) Effectiveness of psychoeducational interventions for family carers of people with psychosis: a systematic review and meta-analysis', *Clinical Psychology Review*, 56: 13-24
- <sup>5</sup> Ma, C.F. et al. (2020) Cognitive behavioural family intervention for people diagnosed with severe mental illness and their families: a systematic review and meta-analysis of randomized controlled trials, *Journal of Psychiatric Mental Health*, 27: 128-139
- <sup>6</sup> Sampogna et al. (2023) Psychosocial interventions for carers of people with severe mental and substance use disorders: a systematic review and meta-analysis, *European Psychiatry*, 66(1): e98 1-20
- <sup>7</sup> Yesefu-Udechuku, A. et al. (2015) Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis, *The British Journal of Psychiatry*, 206: 268-274
- <sup>8</sup> Barbeito, S. et al. (2019) A systematic review of online interventions for families of patients with severe mental disorders, *Journal of Affective Disorders*, 263: 147-154
- <sup>9</sup> Onwumere, J. et al. (2018) Digital technology for caregivers of people with psychosis: systematic review, *JMIR Mental Health*, 5(3): e55
- <sup>10</sup> NICE (2014) 'Psychosis and schizophrenia in adults: The NICE guideline on treatment and management'
- <sup>11</sup> NICE (2015) 'Psychosis and schizophrenia in adults: Quality standard'