

# Mental Health Unpaid Carers Charter

Around 1.5 million people care for someone with mental ill health in the UK.1

We estimate the monetary value of the support provided by these unpaid carers is over £15.1bn<sup>2</sup> – although for those they care for, it is invaluable.

Nearly 80% of all carers feel stressed and anxious<sup>3</sup>, and for many carers of people severely affected by mental illness, caring can be very distressing.

As well as providing emotional and practical support to family members and friends, they may also have additional challenges such as assisting a loved one through a mental health crisis or helping them cope with challenging conditions and suicidal thoughts. Many might be dealing with the stigma and discrimination of looking after someone living with a mental illness, and to add to this, may have their own financial burdens while they are caring.

These carers may also often battle to prevent their relationships with loved ones breaking down, while they strive to help those they care for establish and maintain independence in their lives.

For older carers there is the added worry of what will happen to their loved one when they die or can no longer support them.

This Charter was developed by Rethink Mental Illness' Carers Advisory Board. It outlines the need for the development and implementation of a robust evidence-based carers' framework and standards, mandating all providers of mental health care to proactively involve carers in all settings.

Carers must be involved in the development and monitoring of the framework and standards and hold providers to account.

- 1 NHS Digital (2022) Personal Social Services Survey of Adult Carers in England (2021-2022)
- 2 Calculations based on figures from Carers UK (2021) Valuing carers 2021 England and Wales
- 3 State of Caring Survey 2023, Carers UK



#### Mental health carers must be:

#### **1.** Involved, listened to and treated respectfully by services

Carers' expansive knowledge of their loved one's condition is often undervalued and ignored, with confidentiality frequently cited as a barrier to their involvement in discussions and decision making.

Local health systems must also be properly held to account for their involvement of carers in decisions relating to the person they care for.

# 2. Treated as partners in care by health and care professionals, who have received appropriate training to support this approach

Carers' experiences suggest that health and care professionals do not receive enough specific education and training on how to involve, support and effectively communicate with carers.

A comprehensive training offer for health and social care staff would help to foster a culture of partnership between professionals and carers.

## 3. Offered full access to specialist carers support, including help to understand their rights

Being a mental health carer comes with complex and distinct challenges - including managing difficult behaviours, suicide risk, fluctuating support needs, isolation and stigma associated with mental illnesses.

Local authorities increasingly favour generic carers support amid financial pressures. Specialist mental health carers support should be expanded to ensure these carers understand their loved one's condition, feel able to navigate treatment and support, understand their rights, and get support for their own wellbeing.

# 4. Supported to avoid financial hardship while undertaking a caring role

Caring responsibilities can affect people's ability to pursue employment, create worry for those juggling work and care and cause people to have to leave work entirely. Carers Allowance is set at too low a level to prevent unpaid carers from falling into hardship, and doesn't take into account that caring roles may continue into retirement age.

The longer people undertake unpaid care, the greater the financial burden. Social security options for carers, such as Carers Allowance, must be increased and reformed to tackle financial hardship and account for the reality of caring across their life span.

# 5. Understood and assisted according to their individual needs and backgrounds

Every mental health carer is at a different stage of their journey, and all have different needs.

Certain groups, such as older carers, young carers, LGBTQ+ carers and carers from racially minoritised communities face additional challenges when trying to access support. These groups would benefit from more targeted interventions to meet their needs. The voluntary, community, faith and social enterprise sector has a significant role to play in delivering this kind of support.

### 6. Assisted to plan for when they are not there, and for the future of the person they are for

Some adults living with a mental illness rely on older family members, particularly their parents, for unpaid care and support. Many older unpaid carers worry how the person they are caring for will be supported and housed when they are no longer around to provide this help.

These challenges require more focus within conversations between professionals, carers and individuals with care and support needs. Planning for the future should also be core to assessment of care and support needs, for those living with mental illness and their carers.