1. How many mental health carers are there in the UK?

It is estimated that there are up to **1.5 million people in the UK** caring for a relative or friend with a mental health problem. Hence, **1 in every 40 people** is a mental health carer.

These figures include over **50,000 children and young people** looking after someone with a mental health problem in the UK.

2. What proportion do mental health carers represent of the total carer population?

Mental health carers make up to **25%** of the estimated 6 million carers in the UK; **1 in 4 carers are mental health carers.**

There were also 175,000 young carers (ages up to 18) identified in the 2001 Census. Of that number, **29%** (just over 50,000) care for a family member with mental health problems.

3. How many mental health carers are seen by the Trust?

The total number of mental health carers known to The Princess Royal Trust for Carers Centres is **27,603** (06/07 figures). **9%** of all carers seen by the Carers Centre network are mental health carers.

Of this number, **2048** are young carers. Out of all young carers seen by our Centres, **13%** are caring for someone with a mental illness.

4. What are the most common mental health conditions amongst the people cared for?

Our Carers Health Survey 02/03 found that **over 50%** of carers were caring for someone with learning disabilities (e.g. autism), functional mental illness (e.g. schizophrenia), or organic mental illness (e.g. dementia). This would put the UK figure for carers of people with mental illness or learning disability at **over 3 million carers.** A separate study by Keeley & Clarke estimated that “40–50% of all carers provide care for another family member or friend with a mental health problem” or learning disability.

This is divided into:
- **11%** caring for people with dementia,
- **7%** caring for people with psychosis, schizophrenia or depression
8% caring for people with both mental and physical illness or disabilities
14% for people with learning disabilities or an autistic-spectrum disorder.

5. What are the key issues facing mental health carers?

- **Risk of suicide of the person cared for** – particularly for carers of people who experience depression or psychosis, there is a fear and risk that the person cared for will make suicide attempts. Preventing these attempts, or dealing with the aftermath of unsuccessful suicide attempts, places greater emotional strain on mental health carers.

- **Unpredictability** of caring for someone with mental health problem – the nature of mental illness often means that carers are faced with unpredictable (and in a minority of cases, violent) behaviour and personality changes in the people they care for, and need to deal with a “hidden” illness which makes it more difficult to understand. Certainly, the ‘highs’ and ‘lows’ of certain conditions often mean that the physical capabilities of the person may be ‘normal’ while their mental capabilities and emotional state may vary greatly. This means that it is hard to plan for the future when caring for someone with a mental health condition.

- **Stigma of mental illness** – due to common prejudices and misunderstandings around mental health, carers are less likely to discuss caring with friends and family who may be in a position to offer support and help. Mental health carers may well end up isolated trying to cope on their own. This can also act as a barrier to seeking professional support and help.

- **Increased financial burdens** – given that carers may be unable to remain in employment when caring for someone with a mental health problem. Carers’ financial situation may be particularly severe when caring for someone who is spending uncontrollably (as with many severe cases of bipolar disorder, for example). This can result in increased financial strain or even poverty for mental health carers.

- **Confidentiality and information-sharing issues** – mental health carers often experience problems in obtaining sufficient information about the service users’ condition to care effectively. This leaves them undersupported. Carers are frequently marginalised by health and social care professionals who may use patient confidentiality as a reason to ignore them, and their experience and expertise. In The Princess Royal Trust for Carers’ brief survey of mental health carers in 2007, 86% of these carers had been offered no services in their own right before contacting a Carers Centre.

- **Lack of specialised respite** – conventional ‘sitting’ services are often not appropriate or trained to work with mental health service users. There is a marked lack of understanding of how to work with families to provide appropriate respite when mental illness is involved. As a result, mental health carers have less time off from caring, which impacts on their own physical and mental health, and their capacity to care.

- **Impacts on carers’ mental and physical health** - given the above issues, it is unsurprising that mental health carers spend an average of 60 hours per week on caring tasks. Indeed, carers of people with physical and mental problems are “more likely to report high levels of neurotic symptoms than those caring for people with physical problems or old age”, 28% compared with 14%. Isolation from family and friends as a result of the stigma of mental health caring can also lead to depression and anxiety for these carers.
However, this is not exclusive amongst mental health carers; many carers report that their caring role affects their own mental health. From The Princess Royal Trust for Carers’ Health Survey in 2004, among carers who responded:

- 38% reported suffering stress/nervous tension
- 28% reported suffering from depression
- 27% reported suffering from anxiety

This was in addition to other health problems reported, such as high blood pressure or back injury. In this way, an element of mental ill health will be involved in the vast majority of all caring situations, given the stresses and responsibilities involved in caring.

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2. This figure was derived from two sources: (a) “1 in 6 people will currently be experiencing problems with their mental health.” - from [http://www.shift.org.uk/](http://www.shift.org.uk/) accessed at 15:27pm GMT standard, 23/5/07.
6. See III.
7. The Princess Royal Trust for Carers Carers Health Survey 02/03, p.2, 2005, Partners in Care Handbook, produced by the Royal College of Psychiatrists. The survey data was based on 1066 interviews.
10. See VII, p.165.
11. Survey carried out in September 2007 by The Princess Royal Trust for Carers, undertaken in City and Hackney, Hammersmith and Fulham, Medway, Reading and Central Berkshire, Sedgefield, Suffolk, and West Wiltshire Carers Centres. 54 mental health carers in total were surveyed by these Centres on this question.
“Fewer than one in five carers (19%) know of respite services in their area that would allow them to take a short break from their caring role.”, from “Who Cares?”, p.3, 2005, Rethink Publication, available at http://www.mentalhealthshop.org/products/rethink_publications/who_cares.html

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