

# The Inside Story

*The Impact of Depression on Daily Life*



*The development of this survey and the report into its findings were undertaken in partnership with and funded by Servier Laboratories Limited*



# The Inside Story: The Impact of Depression on Daily Life

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# The Inside Story: The Impact of Depression on Daily Life



## Foreword



As the UK's leading charity for people affected by depression, Depression Alliance is often the first point of contact for people with depression who have experienced discrimination at work. In order to investigate this issue in more depth, to establish the extent of the problem with the help of Servier Laboratories Limited, we were delighted to conduct the 'Inside Story' survey. The results of this survey are highlighted in this report with the hope of enabling people with depression to reach their full potential in the workplace.

Work, whether in paid employment or at college, is an important part of life for most of us and people with depression are no different – indeed in this latest research nearly half of all respondents believe work has actually helped their depression. Testament to passion behind this issue is the number of respondents to whom we are very grateful for taking the time to complete the 'Inside Story' survey. Yet in the UK there has been surprisingly little research into the social and economic impact of depression.

Depression Alliance constantly campaigns for better understanding of the impact of the condition on all aspects of quality of life, including on employment and education. We do believe we are making some progress (to which some of the positive aspects of this report will testify), but feedback from our members is that there is still significant improvement which can be made. Particularly worrying is the ongoing problem of stigma related to depression in the workplace and that a third of the people we surveyed report bullying.

Specifically we are calling for greater recognition that work is very important to people with depression, that they want to and can contribute significantly to the UK economy and that being in work can help them overcome their condition. But a greater understanding of the challenges they face is needed alongside the provision of more support at work to help them contribute fully.

This report forms the first stage of an ongoing research project which will look at the impact on a wide range of quality of life issues and the impact of various types of treatments including a Cognitive Behavioural Therapy (CBT) workbook and computerised package.

Emer O'Neill  
Chief Executive  
Depression Alliance



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## Introduction

As far back as 1997, the World Health Organization (WHO) considered that depression was the second greatest cause of disability in the world.<sup>1</sup> This view was reinforced by major research led by the WHO and published in 2007<sup>2</sup> in which the burden of depression was compared with that of chronic illnesses including angina, arthritis, asthma and diabetes. In this research nearly a quarter of a million people in 60 countries were studied; after allowing for socioeconomic factors and other health conditions, depression had the largest effect on worsening health, and people with depression in addition to another chronic illness had the worst health measures of all disease states.

Medical conditions like depression that are chronic or follow a pattern of remission and relapse are associated with illness-related burdens that fall into two broad categories. The first is the burden of ill-health experienced by the person affected, including discomfort, pain or distress, or difficulties in carrying out the activities of daily life. The second is the wider economic burden which includes the cost of providing health and social care, loss of productivity and time off work, the burden on caregivers, and loss of wages or reliance on state benefits. In this context, depression has been described as a condition that is “chronic and recurrent in nature, impairs family life, reduces social adjustment, and is a burden on the community”.<sup>3</sup>

The burden of depression is high partly because it is very common. The National Institute for Health and Clinical Excellence (NICE) estimates that 9.8% of 16 to 65 year olds in the UK are suffering from mixed depression and anxiety.<sup>4</sup> One in five people affected by depression will not recover fully from a first episode, and in 70–80% of those achieving remission, depression will recur at least once. The long-term recurring nature of depression magnifies its wider economic burden.

People with depression can find it difficult to engage in social activities, including family life and work. In addition to high healthcare costs, the disability associated with depression can limit the activities and productivity of affected individuals and is greater than that reported with other chronic physical illnesses.<sup>5,6</sup>

The impact of depression on work has been measured in terms of absence from work and lost productivity. Research in the mid-1990s which examined the impact of illness in the workplace found that the

average number of days of work lost per year was greater with depression than with chronic illnesses like diabetes, high blood pressure, back pain, and heart disease.<sup>7</sup>

### The economic burden of depression: the costs of healthcare

Most research into the economic burden of depression has focused on the increased costs of healthcare. Not surprisingly, the healthcare costs associated with depression are significant, with increases in the use of all sectors of healthcare provision.

Research in the USA showed that depression is associated with much higher costs in every aspect of healthcare, and are not simply because of the use of specialist mental health services, nor the additional costs of antidepressant medicines.<sup>8</sup> Similar findings were made in a community based study in Sweden, where people who were prescribed antidepressants consumed health resources disproportionately: although only 4% were prescribed an antidepressant, they accounted for 13% of all GP visits, 14% of all hospital beds occupied, and 24% of all medicines prescribed.<sup>9</sup>

In the UK it is surprising how little research into the social and economic burden of depression has been conducted. NICE accepts that the indirect costs of lost productivity due to depression far outweigh the health service costs. The most recent economic review put the total cost of depression to the UK economy in the year 2000 at over £9 billion: only £370 million was allocated to direct NHS costs, the rest was made up of indirect costs including 109.7 million working days lost and 2,615 deaths due to depression.<sup>10</sup>

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## Quality of life: the intangible burden of depression

Research has shown that people with depression have impaired physical, social and work functioning compared with non-depressed people, and that the impact of depression on quality of life is related to the severity of the depression. Some aspects of depression can be considered to be intangible and are difficult to measure. These include pain, suffering and stress on family, friends, caregivers and other

relationships, which may manifest themselves as disruptions in daily activities, family or marital breakdown, and even homelessness. Because these intangible burdens are complex and notoriously difficult to measure, they are generally not included in estimates of the cost of depression, and formal estimates of both the direct and indirect costs of depression are likely to underestimate the true economic impact of depression on society.

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# The Inside Story: The Impact of Depression on Daily Life

## *'Inside Story' survey – executive summary*

A survey of the membership of Depression Alliance was undertaken to investigate the impact of depression on their work and daily lives providing useful information that might otherwise not readily be obtained. The survey was designed to investigate a range of issues including work, quality of sleep, the distress caused by depression and the impact of depression on quality of life and daily activities. In February 2008, 1,200 copies of the 'Inside Story' survey were sent to Depression Alliance members: 288 were returned and were usable. Of these, 96.4% of the respondents had been diagnosed at some time with depression, over two thirds (71%) of them were female. The development of this survey and the report into its findings were undertaken in partnership with and funded by Servier Laboratories Limited.

### **Impact of depression on employment**

There are several work related aspects of this survey that give grounds for optimism, but, unfortunately, others that give rise to concerns. Particularly worrying is the stigma related to depression that is experienced in the work-place, with 79% of respondents worried that disclosing their depression to colleagues could be detrimental to them, and a third of respondents think they have been turned down for a job because of their depression.

### **Employment: grounds for concern**

- The stigma related to depression is a worryingly common concern of respondents
  - 79% of respondents feel that disclosing their depression at work or in college could be detrimental to them.
  - Nearly one third of respondents (32.3%) think they have been turned down for a job because of their depression.
- The lack of support at work available to people with depression is also extremely worrying
  - Over one third of respondents (37%) feel that support was seldom or never available when they needed it.
  - 36% of respondents consider that their depression has made them feel like leaving work.
  - Nearly one respondent in three considers that they seldom or never receive the support they require.
  - When asked what support they would like to be available to them at work, the three most common responses were flexitime, cover for time off, and counselling or other support from occupational health. However, flexitime and cover for time off were reported to be available to less than 30% of respondents.

- The most common factor considered by respondents to make their depression worse is high workload, followed by long hours and poor relationships with management.
- Nearly a third of respondents reported bullying.
- Over one third of respondents have chosen to leave a job because of their depression.
- The reaction of management or college staff was described as being frustrated, patronising, or difficult by one respondent in 20.

### **Employment: some grounds for optimism?**

- Over 70% of the respondents were either employed or retired and only one person in 20 was unemployed and seeking work.
- Nearly half of respondents (46%) consider that being in work helps their depression.
- The majority of respondents (over 50% in each case) state that they are seldom or never:
  - avoided by colleagues
  - discouraged from taking on projects
  - the object of snide or sarcastic comments
  - passed over for promotion
  - monitored more than other employees.
- Respondents felt able to be open about their depression:
  - Less than one percent of respondents stated that nobody in work knew that they had depression.
  - Personnel departments had been informed in a quarter of cases, a similar number had told their peers, and supervisors had been informed in nearly 40% of cases.
- The reaction of management or college staff was described as being accommodating and helpful by one respondent in three.
- About one person in four thinks that they always or often receive the support they need.

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- Counselling or support from occupational health was available in a similar proportion of cases to those who desired it.

While there is significant room for improvement there are a few indicators that things might be improving in the workplace.

## **Respondent's subjective experiences of depression: impact on quality of life and daily activities**

A consistent finding of this survey is that the majority of respondents (over 60% in each case) consider that five aspects of depression have a severe or very severe effect on distress, quality of life and their ability to perform daily activities. These are:

- anxiety
- loss of interest
- low energy
- poor concentration
- poor sleep.

The findings for sadness are less consistent – although considered distressing and having a severe impact on quality of life, it has less of an impact on daily activities. Low sex drive and altered appetite were moderately distressing and had a moderate impact on quality of life, but had little or no impact on daily activities for most respondents.

## **The relationship between sleep, depression and employment**

The survey has highlighted the impact disturbed sleep has on the working lives of people with depression, their quality of life, and their ability to perform daily activities. A large majority of respondents (83%) stated that their work is adversely affected by poor quality of sleep, which is an important consideration in the ongoing management of these patients. In addition, when depressed, 62% consider disturbed sleep to cause severe or very severe distress, 65% think it has a severe or very severe impact on their quality of life, and 60% said poor sleep has a severe or very severe impact on their ability to carry out daily activities. Sleep disturbance can have a major impact in people with depression, and this data highlights the importance of healthcare professionals and patients working in partnership to manage their depression in a way that will not impact negatively on their sleep.

## **Recommendations resulting from this research**

### **Tackling stigma and improving work opportunities and experience**

1. Employers should review their policies and procedures to ensure that high standards for anti-discriminatory, anti-oppressive and inclusive practice are applied in all aspects of employment including recruitment, management, occupational health and personal development.
2. Employers should provide training/education/information to all their staff about depression and its impact and how they can help colleagues affected by it.
3. Employers should work pro-actively to ensure that employees with depression receive support that is commensurate with their needs.
  - The support systems advocated by respondents were: flexitime, cover for time off, and counselling or other support from occupational health.
4. Employers should ensure that staff members do not feel threatened in their working environments and that working hours and workloads are not excessive.
5. Occupational health services should work proactively with people with depression, offering and co-ordinating support within the work environment, and paying particular attention to quality of sleep.

### **Addressing the subjective experiences of depression that cause the greatest burdens**

Doctors and other health professionals involved in the treatment of depression should pay more attention to aspects of depression that may persist and impair work performance, quality of life, and the ability to perform daily activities. These aspects may include anxiety, loss of interest, low energy, poor concentration, and poor sleep. Particular attention should be paid to developing better ways of managing and treating disturbed sleep associated with depression. Furthermore, government policy should encourage the use of drugs and psychotherapy that could help enable people with depression to return to work.



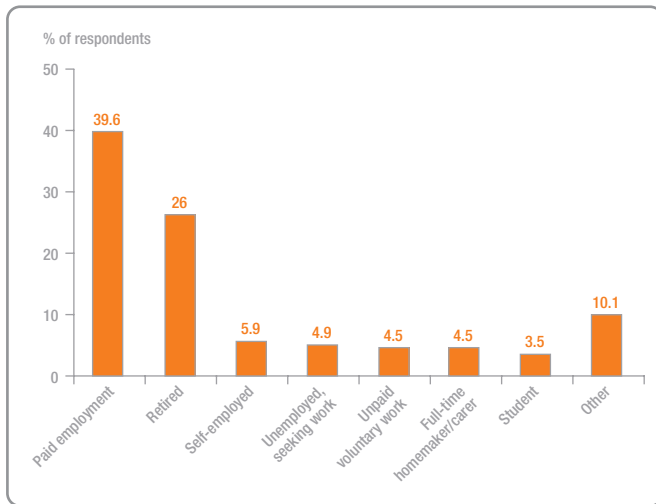
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## 'Inside Story' survey – full results

### Employment

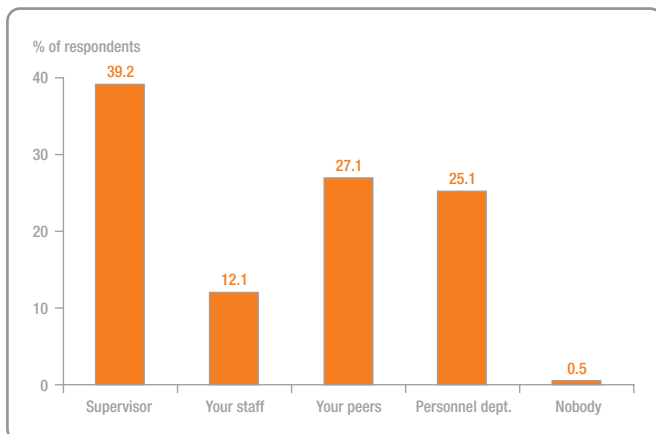
Over 70% of the respondents were either employed or retired, with only one person in 20 unemployed and seeking work (Figure 1).

**Figure 1. Employment:**  
Are you currently in employment/education?



Of the respondents 79% felt that disclosing their depression at work or in college could be detrimental to them, although less than 1% of respondents stated that nobody in work knew that they had depression. Personnel departments had been informed in a quarter of cases, a similar number had told their peers, and supervisors had been informed in nearly 40% of cases (Figure 2).

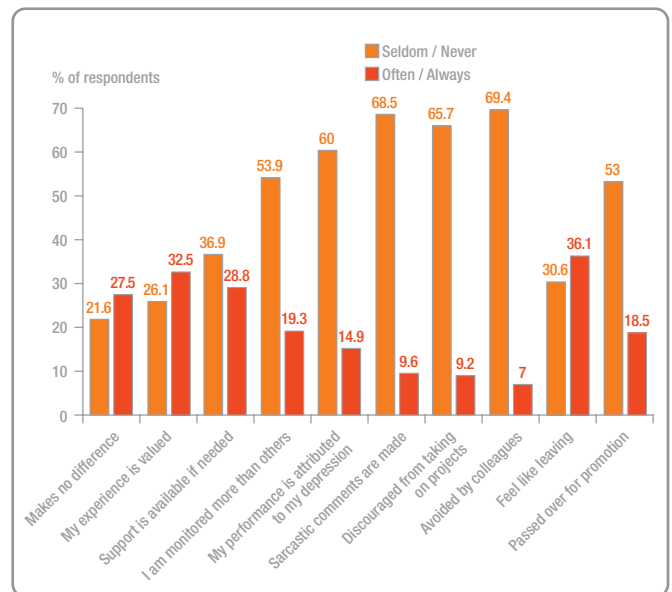
**Figure 2. Employment:**  
Who at work knows that you experience depression?



### Effect of depression on employment or studies

While experience of work can be positive there is room for improvement. The majority of respondents (over 50% in each case) stated that they were seldom or never avoided by colleagues, discouraged from taking on projects, the object of snide or sarcastic comments, passed over for promotion or monitored more than other employees. However, over one third of respondents (37%) felt that support was seldom or never available when they needed it, and a similar proportion (36%) considered that their depression had made them feel like leaving work (Figure 3).

**Figure 3. Employment:**  
What effect has depression had on your employment/studies?



### Attitude of management or college staff

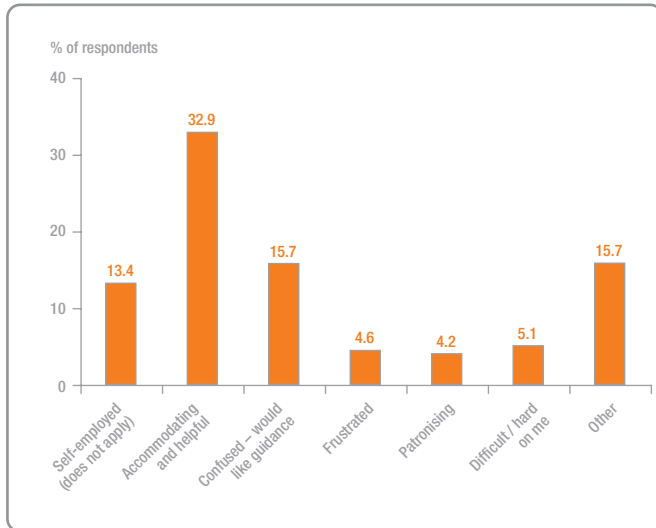
The reaction of management or college staff was described as being accommodating and helpful by one respondent in three, with only one in 20 describing them as being frustrated, patronising, or difficult (Figure 4). Sixteen percent of respondents thought that their management was confused about the condition and would like more guidance. Taken together these results suggest that a positive change has partially been achieved, which is to be welcomed, however, there is still significant room for improvement.



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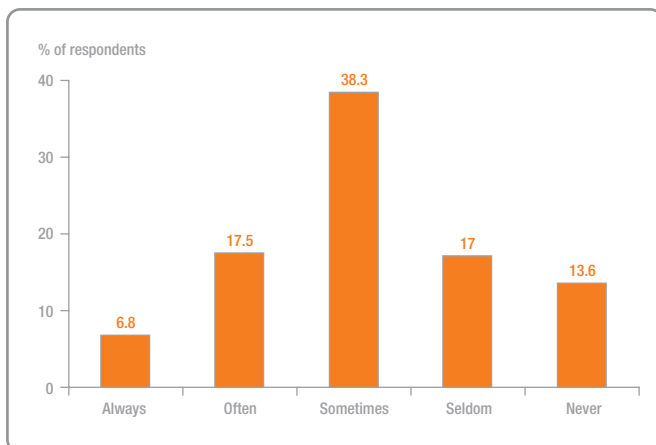
**Figure 4. Employment:**  
*Which best describes the reaction of your management/college?*



## Support available to people with depression

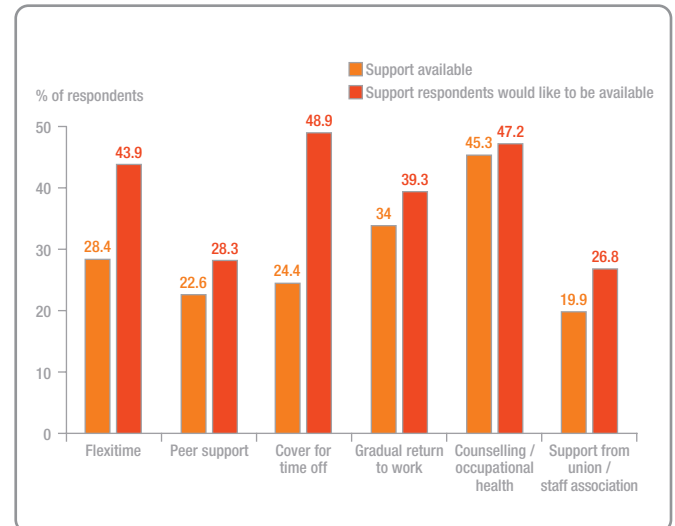
Unfortunately the positive experiences described above are not reflected in the amount of support that people consider they receive. Less than one person in four thinks that they always or often receive the support they need, while nearly one in three considers that they seldom or never receive the support they require (Figure 5).

**Figure 5. Employment:**  
*Do you think you get the support you need at work/ college?*



When asked what support they would like to be available to them at work, the three most common responses were flexitime, cover for time off, and counselling or other support from occupational health. Of these, only counselling or support from occupational health were available in a similar proportion of cases to those who desired it. Flexitime and cover for time off were reported to be available by less than 30% of respondents (Figure 6).

**Figure 6. Employment:**  
*If you work, what support is available from your employer?*



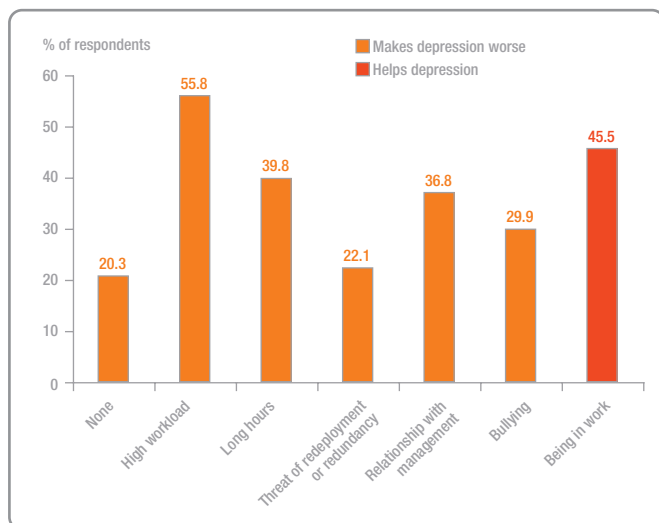
## Work-related factors that affect depression

The most common factor considered to make depression worse is high workload, followed by long hours and poor relationships with management. Nearly a third of respondents reported bullying. One respondent in five reported that work did not have a negative impact on their depression, and nearly half of them (46%) considered that being in work helped their depression (Figure 7).



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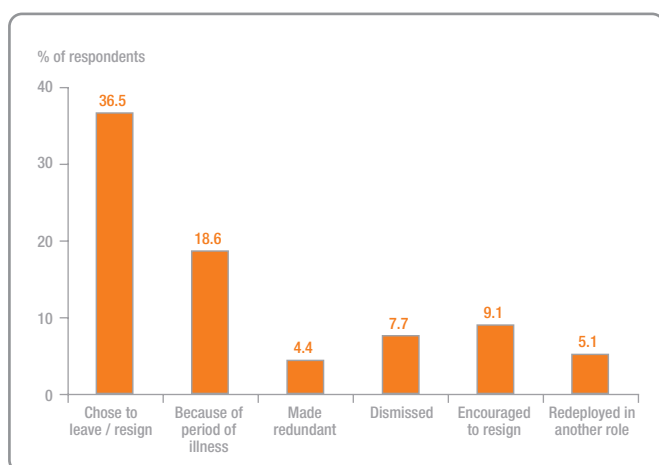
**Figure 7. Employment:**  
*Factors at work/college that have affected depression*



### Depression and loss of employment

Nearly one third of respondents (32.3%) thought that they had been turned down for a job because of their depression. Over one third had chosen to leave a job because of their depression, and a few had either been dismissed or made redundant because of their depression (Figure 8).

**Figure 8. Employment:**  
*Have you ever lost a job/course as a result of your depression?*

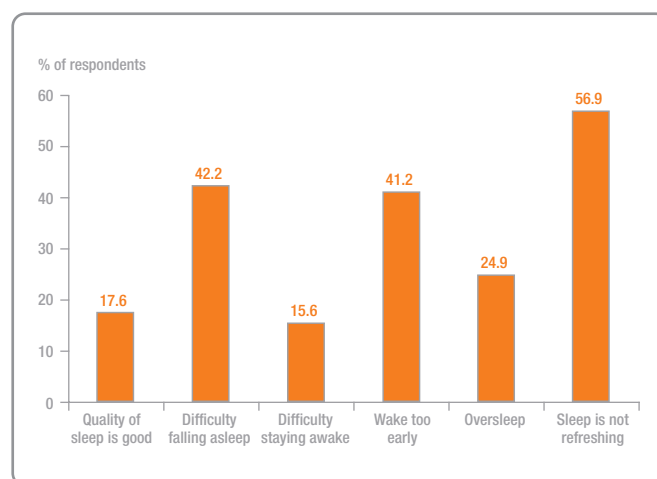


### Quality of sleep

A large majority of respondents (82.5%) stated that their work was adversely affected by poor quality of sleep.

Only 18% stated that the quality of their sleep was good. Over half (57%) said their sleep was not refreshing and over 40% had difficulty in falling asleep or experienced early morning waking (Figure 9). These descriptions can be characteristic of the illness of depression, and highlights the importance of addressing disturbed sleep as part of the overall management of depressed patients.

**Figure 9. Quality of sleep:**  
*What is the quality of your sleep?*



### Subjective experiences of depression

Respondents were asked to consider their subjective experiences of a range of aspects that contribute to the syndrome of depression. These were: low energy, anxiety, loss of interest, sadness, poor concentration, poor sleep, low sex drive, and altered appetite. They were asked to rate the impact these aspects had when they were depressed on the level of distress they experienced, their quality of life, and their ability to carry out daily activities.

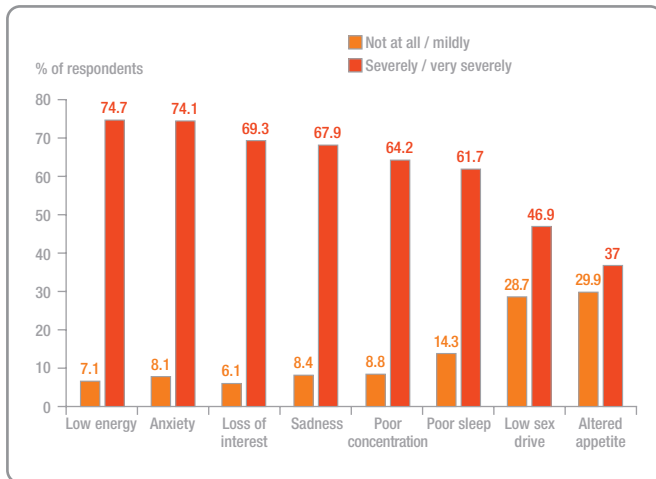
### Subjective distress of depression

The following were considered to be severely or very severely distressing by the majority of respondents (over 60% in each case): low energy, anxiety, loss of interest, sadness, poor concentration, and poor sleep. A minority of respondents considered low sex drive and altered appetite to be severely or very severely distressing (Figure 10).

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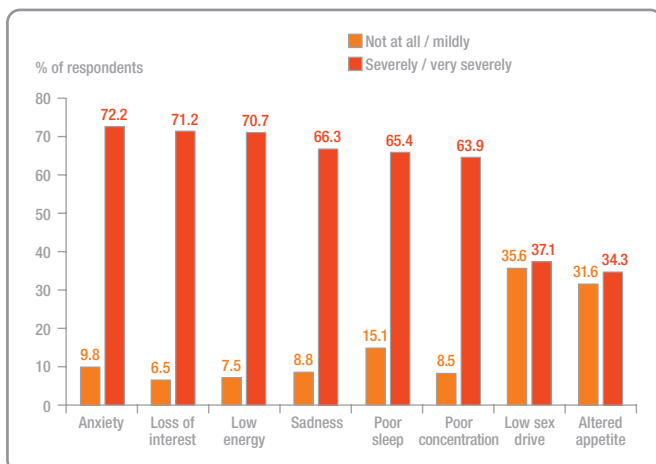
**Figure 10. Distress caused by depression:**  
When you are depressed how distressing are the following?



## Subjective impact of depression on quality of life

A similar pattern was observed for the impact of depression on quality of life. Again, low energy, anxiety, loss of interest, sadness, poor concentration, and poor sleep were considered to have a severe or very severe impact on quality of life by the majority of respondents (over 60% in each case). A minority of respondents considered low sex drive and altered appetite to have a severe or very severe impact on their quality of life, similar proportions to those who considered these aspects to have little or no impact on the quality of life (Figure 11).

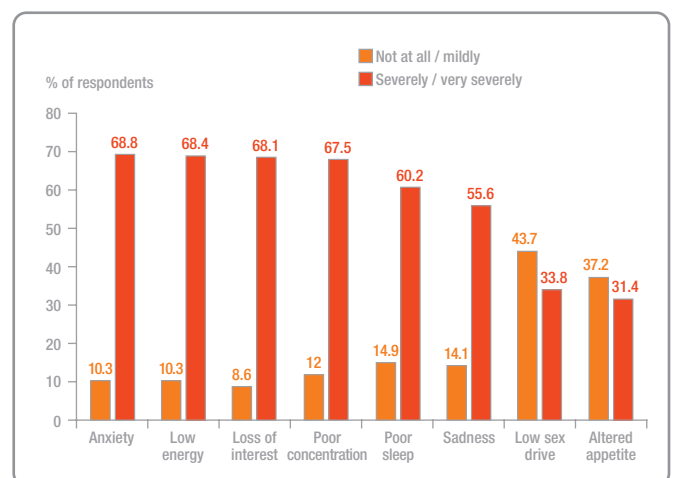
**Figure 11. Quality of life: impact of depression:**  
When you are depressed how much of an impact on your quality of life are the following?



## Impact of depression on daily activities

A similar pattern was again observed for the impact of depression on the ability to carry out daily activities. Low energy, anxiety, loss of interest, poor concentration, and poor sleep were considered to have a severe or very severe impact on the ability to carry out daily activities by the majority of respondents (over 60% in each case). The impact of sadness on daily activities was slightly less than on subjective distress or quality of life. The impact of low sex drive and altered appetite on daily activities was considered to be much less than on subjective distress and quality of life, with more respondents stating that these aspects had no impact or only a mild impact (Figure 12).

**Figure 12. Daily activities: impact of depression:**  
When you are depressed how much of an impact on your daily activities are the following?



These results represent the initial phase of an ongoing project. The second phase of the research will be undertaken by Depression Alliance and examine the effectiveness of different types of non-pharmacological support in helping depression. Phase two results are expected in the summer of 2008.

Depression Alliance and Servier Laboratories Limited are grateful to David Purves for analysing the 'Inside Story' survey results.



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