

### Key Points

1. Many factors may influence a person's decision to reveal to an employer that they are dealing with a chronic illness
2. Study surveyed every employee at a University in the United Kingdom regarding chronic illness and whether they had told their immediate boss
3. 734 out of 5000 reported managing a chronic illness while working there
4. Altogether, about 50% had reported their illness to some extent to their boss
5. Factors related to partial disclosure included being in an academic job, having diabetes, and scoring high on the experience of chronic illness scale
6. Factors related to full disclosure were the perceived importance of workplace support and whether colleagues were aware of the chronic illness
7. Authors believe that most people only reveal an illness if there is a clear need to do so and share information on a need to know basis

### Source

Munir F, Leka S, Griffiths A. Dealing with self-management of chronic illness at work: predictors for self-disclosure. *Soc Sci Med.* 2005 Mar;60(6):1397-407.

## Survey: Revealing Chronic Illness to Employers

It's an issue every working adult with Chiari has faced...what, when, and how much to tell your employer about your condition. Clearly, some issues are forced; HR must be notified if there will be an extended absence or if there are insurance issues, but how much do you tell your boss about what is going on?

In facing this issue, Chiari people are far from alone. In fact, some researchers estimate that by age 50, up to one-third of the workforce is managing some type of chronic illness - such as cardiovascular disease - in the workplace. Each one of these people faces the same issue about what and how much to disclose to their boss.

The decision is not always easy; some illnesses are essentially invisible, while others may require the overt use of medicines or special equipment at work. So to some, there is a benefit - if not an outright need - to disclosing an illness at work. In a supportive company, allowances may be made for reduced hours, modified workload, and time off for doctors visits.

However, there can also be negatives associated with disclosure. Some illnesses retain a certain stigma, such as psychological disorders, Irritable Bowel Syndrome, and HIV/AIDS. In a non-supportive work environment, an employee who discloses an illness may feel ostracized or even fear losing their job.

Dr. Fehmidah Munir, a health psychologist at the Institute of Work, Health, and Organization, at the University of Nottingham, U.K., studies issues surrounding chronic illness in the workplace such as this. Dr. Munir, and her colleagues, decided to research what factors predict whether an employee will disclose a chronic illness to their boss, by surveying every employee at a university in the U.K. They reported their results in the March, 2005 issue of the journal *Social Science & Medicine*.

The research team first studied the existing literature on the subject and conducted in-depth interviews with 15 employees who were managing a chronic illness while working at the University. From this, they developed a questionnaire designed to measure six broad categories (see Table 1): the chronic illness experience, its effect on work, absence from work, disclosure and support, demographic information, and work adjustments sought and received.

The survey was sent to every employee - about 5,000 - of the University. Forty-four percent (2,172) of the employees returned the survey - sufficient to validate the study - and of those, 734 (34%) reported managing a chronic illness during their employment. From these responses, the research team identified several illness categories: depression/anxiety, asthma, musculoskeletal pain, irritable bowel syndrome, arthritis, migraine, heart disease, and diabetes. Illnesses with a very small number of respondents were grouped into an Other category and responses which didn't identify the specific illness were grouped in an Unknown category. The Other and Unknown categories were dropped from the subsequent data analysis, so in the end 610 surveys were used.

**Table 1**  
**Description of Questionnaire Used**

- Measured 6 categories
  - Developed by conducting in-depth interviews with employees with chronic illnesses to identify their issues
1. **Chronic Illness** - Self-report any chronic illness (examples were given); also asked how long they have had it; the severity, how often they experience symptoms, whether they had been diagnosed by a doctor, whether work was an aggravating factor, whether they used medicine or special equipment, and whether they needed time off from work
  2. **Effect On Work** - Asked if illness effected their work and how often they were unable to function normally at work
  3. **Absence** - Asked the number of times they had been absent from work over the prior 12 months
  4. **Disclosure And Support** - Asked whether they had disclosed their illness to their boss (partial) and explained the illness' impact on their work (full); also asked to rate the importance of receiving different types of support from the workplace
  5. **Demographics** - Age, gender, occupation, and length of employment
  6. **Work Adjustments Sought and Received** - This category was not discussed in this paper
- Sent to 5000 people (every employee)

- 44% responded to the survey
- 735 reported a chronic illness
- Data from 610 was used for analysis

Next, the researchers entered the data from the 610 surveys into a statistical model for analysis. Specifically, they wanted to determine what factors influenced whether employees disclosed their illness to their boss. For the purposes of the analysis, partial disclosure was defined as revealing the presence of a chronic illness to an immediate supervisor. Full disclosure was defined as revealing the chronic illness and discussing its impact on the employee's work.

The team found that overall 26% reported they had partially disclosed their illness to their boss, while 24% reported full disclosure. While in general demographics did not appear to influence disclosure, people in a non-academic job were three times more likely to partially disclose their illness than academics. The authors speculate that the academic employees (professors) enjoy enough flexibility in their work environment - meaning they can work flexible hours or work from home - that they don't have to disclose their illness.

Another factor which influenced partial disclosure was a high score on the chronic illness experience, meaning the illness was moderate or severe and required medication or the use of special equipment. Interestingly, the type of disease did not matter except for diabetes. Those with diabetes were more likely to partially disclose this fact to their boss than those with other illnesses (see Table 2).

Two factors were related to full disclosure: the importance of receiving support at work and whether colleagues were already aware of the illness. When an employee perceived that workplace support was important, they were more likely to fully disclose their illness. Similarly, if colleagues already had been told, they were more likely to tell their boss about their situation.

**Table 2**  
**Disclosure By Chronic Illness Category (734 Respondents)**

Illness	# of Respondents w/illness	% Who disclosed illness to boss
Depression, anxiety	124	37%
Asthma	96	47%
Musculo-skeletal pain	95	57%
Iritable Bowel Syndrome	78	37%
Arthritis	44	54%
Migraine	44	59%
Heart Disease	37	55%
Diabetes	37	84%
Other	69	-
Unknown	55	-

**Notes:** The respondents from the Other and Unknown categories were not included in the subsequent data analysis

The researchers believe the results mean that in general, most people adopt a strategy of only revealing their illness if there is a need or it can not be hidden. For example, they need time off for doctor's appointments or it is obvious they are checking their blood sugar levels frequently.

Further, they believe that people only reveal information on a need to know basis, preferring partial disclosure unless they feel the need for support in the workplace or if their colleagues already know.

The authors readily acknowledge several limitations to their research, including the low response rate, the fact that the questionnaires were limited in what they could ask, and that they didn't address the barriers to disclosure. Despite these limitations, the study offers an interesting glimpse into how people handle the issue of if, and what, to tell their employer about a chronic illness.

