Disclosure – Telling Other people About Your Schizophrenia

This information sheet covers telling people you know, such as work colleagues, friends and neighbours about your schizophrenia. It does not cover disclosing to the DVLA regarding driving licences or insurance companies, nor does it cover disclosing to a current or prospective employer, which is dealt with in our information sheet on getting into work.

Disclosure – the act of telling other people about your mental illness is an issue that is vital to a successful recovery strategy. Get it right, and you will be able to assemble around you a group of supportive people who can help you with your struggle. Get it wrong, and you risk alienating those people, making your life even more complicated than it is already.

Sharing your diagnosis can have advantages and disadvantages and both must be weighed up carefully. Remember that, ultimately, it is your call and, if you are in any doubt, it may be best to keep it private – at least for the time being. Once you have told someone you cannot “un-tell” them; the genie is then very much out of the bottle. Make no mistake: telling someone that you have schizophrenia is very different from telling people that you have asthma or diabetes.

Many people living with schizophrenia find that when they have come out of their crisis and are on the road to recovery they feel a need to tell people about their illness and to explain to them why their relationship with them was disrupted. They may feel guilty or embarrassed by their bizarre behaviour while they were psychotic and feel that they owe their friends an explanation. Confession, they say, is good for the soul.

Be very wary of these feelings. Any decision to tell someone about a condition with such serious implications for so many aspects of your life must be made on the basis of a serious and cool-headed assessment of the benefits that such disclosure will have for you and those close to you, as well as any adverse consequences, such as discrimination, that may arise in the future. Feelings of guilt or embarrassment should not play any part in this decision.²

However, whilst guilt should not play a part in your decision to disclose, it may be that you will feel that providing an explanation about your previous bizarre or disturbed behaviour to people close to you will help them to understand why the problems arose and to relate to you better in the future. This is a constructive approach that can, if handled carefully and sensitively, help to reconcile you with people who have distanced themselves from you because of your past behaviour.

If you have close family or friends who have stuck by you through your crisis, you should also give some thought to the effect that disclosure would have on them. They may initially be opposed to you telling other people and it may need some careful negotiation to get their agreement.

So Why Tell People You Have Schizophrenia?

Before telling someone about your condition, the first question to ask is why should I tell this person? Do they really need to know and will telling them help you in your recovery, or will it cause you additional problems?

One very good reason to tell people about your schizophrenia is that they can then become part of your support network and will be able to look out for you in the future. They will be able to spot if anything changes in your behaviour and will know when to get help. They may also be able to make allowances for you if you are not performing as well as normal. However, if you are in any doubt as to how they will respond, or if you feel that there is any chance that they will react badly, then you should think twice
about telling them.

In addition, if you are working in any organisation, be it work, college or voluntary work, disclosing correctly can be a useful precaution against malicious rumours circulating about you later on.²

**Whom Should You Tell About Mental Illness?**

In assessing whom to tell there, are a number of useful questions that you can ask beforehand about the person, such as

- Are they likely to be sympathetic or hostile?
- Will they be supportive in the future?
- Are they likely to talk to anyone else about it?¹
- Are they likely to use the information against you?⁷

You may also consider a couple of important issues, such as:

- Is the person likely to find out anyway?
- If you do not tell them will they be able to trust you on other things?
- Will not telling them make it more difficult to relate to them in the future?³

A study carried out in 2011 in the USA found that in almost 40% of cases, a police officer would be more likely to treat people worse if they knew about their schizophrenia, with the figures for employers and work colleagues being about the same. You are on safer ground with parents and friends, however, with only about 20% of them treating people they know to have schizophrenia poorly.

However, the same study also found that about 30% of police officers would treat people better if they knew that they were living with schizophrenia, whilst only 13% of work colleagues and 18% of employers would treat them better.⁹

**Partners**

If you are single, then at some point in your recovery you will naturally start to think about dating again and the issue of whether or when to tell your new partner arises. This can be a difficult issue. If you tell them and they react badly, the relationship may come to an abrupt end. On the other hand, if you hold the truth back for too long they may see this as dishonesty and find it difficult to trust you in the future.

These fears are far from groundless. A recent survey carried out for the Time to Change campaign found that people would be four times more likely to leave a partner because of a mental health problem than a physical disability.⁶ We have to face up to telling our partners at some time, difficult though it may be. Choosing the right time and the right way to tell them will need the utmost care.

**Employers**

If you are looking for work you need to think about disclosing to any future employer. However, there are ways of doing this, that won’t put you at an enormous disadvantage. This subject is covered in much more detail in our advice sheets on Getting Into Work.

**Work and College Colleagues**

If you don’t feel able to talk about your mental illness at work, then you are not alone. A survey in 2011,
carried out by the Chartered Institute of Personnel and Development of 2,000 workers, found that only four in ten of them would feel confident in discussing mental health problems with their employer.⁵

Employers and colleagues at work may have pre-existing ideas about what a diagnosis of schizophrenia means. They may be influenced by adverse press reports of people going crazy or becoming dangerous, or they may assume that people with schizophrenia cannot handle certain types of work.⁸

If you are studying at school or college, it may be useful to make an appointment to see the college nurse or mental health support worker (if they have one) and tell them about your condition. In this way, you will be speaking to a medical professional who will have some medical knowledge of schizophrenia and previous experience of working with people with mental illness. If you find that you are having problems later on with deadlines or attendance, they may be able to help by speaking to your tutors and arranging for extra time for you to complete your work. Remember that whatever you tell them is confidential and won't get back to any of the teaching staff. In this way, you can get extra support without having to disclose your problems directly to your lecturers or tutor.²

Similarly, at work, it is often better to tell the work’s nurse or occupational health consultant than to disclose directly to your line manager. Again, you will be talking to a medical professional who will have a much deeper understanding of your problems and who is bound by rules of confidentiality.²

Voluntary Work Colleagues

If you are working voluntarily for a charity or community group, it may be a good idea to tell them, although there is no obligation to do so. In this situation, it is best to identify key individuals in the organisation; the people who really need to know, rather than telling the people that you work alongside.²

Nevertheless, remember that if you are in any doubt about how people will react, or feel unable to make the decision, it is best to err on the side of caution and hold back from telling them.¹

Neighbours

Unless you count your neighbours as good friends, the reasons for telling them are less pressing than, say, work colleagues. However, there may be good reasons to tell them, particularly if they have noticed changes in your life, such as not working, about which they have become curious.

What to tell People About Your Schizophrenia

Sadly, there is still a great deal of misunderstanding and stigma about schizophrenia and it is sometimes best not to use that word when you are telling other people about your problems, but use a more neutral term such as “a breakdown” instead. You should certainly think very carefully before disclosing your full diagnosis to work colleagues or fellow students.

However, it is often a good idea to identify key individuals in an organisation and to make a fuller disclosure to them. When you do tell these key people, it is sometimes a good idea to tell them about how the illness affected you in terms of what kinds of symptoms you had and the kind of suffering that you endured. This will help to put a human face on your problems and will also help them to know what to look out for in the future if you begin to relapse.

You will need to think carefully about how to describe your experiences in neutral, layman’s language that they will be able to understand without getting too alarmed. It isn’t always necessary to tell people that
you once thought that you were Saint Peter!  

If you have been off work for a long time, it may also be a good idea to tell people what you have been doing since you were ill. For instance, tell them that you have made a strong recovery and that you have been able to return to part-time work or voluntary work.

In some cases, it may be a good idea to tell people about your diagnosis and use the schizophrenia word. In this instance, you may also like to think about adding a little bit of background information about schizophrenia to your explanation. For instance, you could tell people that the condition is an illness of the brain, that it is much more common than they may think, that contrary to what they may have heard, people with schizophrenia are not usually dangerous and that most people will recover to some extent.

If you have been away from work or college for a long period, your friends and colleagues will naturally be curious about where you have been and will need an explanation. Sadly, it may also be the case that the workplace grapevine has been over-active in your absence and that there are some exotic rumours going around about why you haven't been seen at work lately. In this case, you will need to provide answers that will satisfy their curiosity.

When to tell people?

It is rarely best to tell people at your first meeting with them. “Hi I'm Johnny and I'm a schizophrenic” will rarely win you any sympathy the first time you meet someone. It is usually best to get to know the other person and let them get to know you over a period of several months before telling them anything.

Working with a group of people for a period of time will also give you a chance to weigh them up and assess the best people to tell, as well as how to tell them. Identifying the key people in any circle who need to be told is one of the most important aspects of disclosure.

How to tell people?

The best way to tell people depends very much on your individual strengths and qualities. If you are a good “people person” and communicate well face-to-face, then a private meeting with them may be a good idea. Make sure they can spend plenty of time with you and that the meeting will not be rushed.

However, if you communicate well in writing, then it may be a good idea to write them a letter. This has the huge advantage that you can spend lots of time composing the letter at leisure and you can think very carefully about exactly what you want to say in it.

Whether you choose to tell them face-to-face or in writing, careful planning and preparation are key. A spontaneous, spur-of-the-moment decision to tell someone is rarely a good idea and can often have disastrous results.

Being Rejected Because of Your Schizophrenia

If you find that a person reacts badly when you tell them about your schizophrenia, it is important not to become judgemental. You may also find that people you thought you knew quite well will simply start to keep their distance from you. I am afraid that it is one of the cruel aspects of this condition that some of your old friends (and maybe family too) will fall by the wayside.

Sometimes people find it difficult to cope with mental illness in others, especially if they have had problems in their own lives. In addition, there is so much stigma surrounding schizophrenia that
misconceptions are inevitable.

In any case, such people are probably not the sort who would be able to respond positively with help for you in the future if you needed it. The task for the future is to assemble around you a circle of people who can cope with your diagnosis and who will be able to respond constructively in the future, should you show any signs of relapse.

References


2. Author’s personal experiences.


