

Recovery Strategies for Schizophrenia

Is Schizophrenia a life sentence?

Many people believe that schizophrenia is a life sentence: that people with schizophrenia will live a life of low achievement and be in constant danger of harming themselves or others. In fact many people with schizophrenia do manage to make substantial recoveries from their symptoms and move on to lead better lives.

When schizophrenia was first described by Dr Emil Krapelin in 1898 he used the term dementia praecox or premature dementia because he saw the condition as one which entailed a progressive worsening of the symptoms and deterioration in functioning. However later many psychiatrists observed that a significant proportion of their patients went on to improve sufficiently well to return to their former lives and that some never experienced any further problems after their first episode of psychosis.¹

Since Krapelin there has been considerable debate among psychiatrists on this issue of recovery and today most psychiatrists hold the more enlightened view that recovery is possible for a significant number of sufferers. It is absolutely key for sufferers and carers alike to understand that a diagnosis of schizophrenia need not necessarily be a life sentence to a life of low fulfilment and poor ambition.

Before we start to discuss recovery there are two important questions that we need to consider. The first is what do we mean by recovery and the second is why do I need to recover?

What do we mean by recovery?

Does recovery mean that schizophrenia can be cured? Schizophrenia cannot be cured in the same way that an infection can be cured with antibiotics. However looking at the outcomes over ten years from diagnosis, a large proportion of people who experience an episode of psychosis (in fact about 25% to 30%) will recover to lead a normal lifestyle and will have no further problems during their lifetime. A further 25% will be much improved on medication. 25% will show some improvement on medication but may experience several relapses and may never be able to work. 15% will lead a chronic course experiencing repeated relapses and being substantially handicapped by their condition.² This leaves the final 10% who sadly will die mainly by their own hand.

Which of these groups you will slot into depends on many factors including not least how good you are at taking your medication. Medication remains the mainstay of treatment in the western world and for most people will provide a high level of security against relapse. However as we will see below a good enduring recovery is dependent on a combination of factors and how good a recovery you make will depend in large part on how good you are at managing all of those elements of your life.

Why do I need to recover?

If you are at an early stage in your illness you may not even accept that you have a problem. This is what psychiatrists call lack of "insight". The delusion that says "I'm not ill" is in many ways the most unhelpful and destructive delusion of all. It is what Gwen Howe in her book, *Serious Mental Illness a Family Affair* calls the "core delusion". It is the one delusion that alone has the power to prevent recovery.³

However as you move on you will develop greater insight and with that insight will come hope: the quality without which you cannot recover. Hope will give you the ability to visualise a better life for yourself. A life of greater independence and better relationships with those around you. Perhaps starting or returning to

study, voluntary work, part-time work or even a full time job. Perhaps greater financial independence and maybe a more active social life and a long term close relationship.⁴

Recovery strategies for schizophrenia

Below we consider two recovery strategies: Living with Schizophrenia's own strategy: I'M TUFRR and the WRAP programme developed in the USA and used widely all over the world including here in the UK. They each have different approaches to recovery. I'M TUFRR looks at the elements that are necessary for a good recovery whereas WRAP provides the practical tools to help you manage your life through periods of wellness and illness. They are both useful tools and can be used separately or together.

But what is common to both is the understanding that to make a good recovery the person with schizophrenia must take a lead role in managing their condition and take some personal responsibility for their recovery. Don't wait for your psychiatrist or Community Psychiatric Nurse to play this role. They simply do not have the time. You must become your own case manager, identifying what needs to change in your life and searching out the resources to achieve it.

By taking responsibility for and an active role in managing your recovery strategy you will own your recovery in a way that you wouldn't if all of the direction was provided by your healthcare workers.

There is a growing realisation amongst doctors, psychiatrists, nurses and other health care workers that they don't have the whole solution and that the patients themselves often have an understanding and awareness of their condition that the medical textbooks simply can't supply. Most doctors nowadays are only too pleased to see patients taking on an active role in managing their own recovery.

I'M TUFRR

I'M TUFRR is a recovery strategy that was developed in the UK by a man who had suffered from a prolonged and very severe episode of psychosis and was able to recover sufficiently well to re-join mainstream society. It enabled him to get back to a normal life with just a few brief relapses and eventually to get back into full time work.⁹

I'M TUFRR (pronounced "I'm tougher") describes the five essential components of the strategy which are:

- I need
- Minimum medication
- Talking therapies
- Useful occupation
- Family and friends support
- Rest and relaxation

Now any one of those elements in isolation may be beneficial but acting together they can be a very powerful therapeutic formula indeed. Let's look at each in turn:



Antipsychotic medicine is the mainstay of treatment for schizophrenia in the NHS and will help about 70% of those people who take it (Image: wavebreakmedia/Shutterstock)

Minimum Medication

Medication is a key element of the strategy and it is no coincidence that it is top of the list. Modern antipsychotics are in most cases extremely effective in lessening the positive symptoms of schizophrenia such as the hallucinations (voices) and the delusions (strange beliefs). In fact about 70% of people will experience a substantial improvement in their positive symptoms when they first start on the antipsychotic medicine. This is about the same degree of effectiveness that penicillin has in treating an infectious illness like pneumonia.⁵

However the mind is an extremely complex organ and the way that these medicines work differs from individual to individual. Some people will respond well to a particular type of antipsychotic but not to another. Dose rates also vary. Some people will do very well on lower doses whereas for others a high dose is needed to achieve the same benefit. However, a small number of people with schizophrenia do not seem to respond to any of the antipsychotics currently available.

The aim then is to find the best type of antipsychotic that works well for you at the minimum dose necessary to reduce the symptoms to the absolute minimum. There is no point in taking a higher dose than is necessary as that would only lead to more problems with side effects. On the other hand taking a low dose which does not adequately control the symptoms would not give you sufficient benefit.

Like most medical treatments antipsychotics do have some unwanted and sometimes unpleasant adverse effects that people usually call side effects. Some of the more common side effects are weight gain, anxiety, restlessness, sexual problems, drowsiness and difficulty concentrating. For more on how to cope with side effects see our Information Sheet: Managing Side Effects of Medication. It is important to realise that most medical treatments for serious physical health problems also have unpleasant side effects.

Unfortunately there is often no alternative to the side effects whether the illness is of the body or the mind. Side effects should be seen as another aspect of the illness that has to be managed by the sufferer. They should never become an excuse to stop taking the medication. Schizophrenia is an extremely disruptive and sometimes destructive condition. It destroys careers, family relationships, reputations and sometimes it kills people. Overcoming such a powerful adversary and moving on to a meaningful life sadly entails some sacrifice such as coping with the side effects.

However the key to this element is finding the right medication at the right dose for you. Antipsychotic

medication doesn't work instantly and it may take several months before the benefits are seen.

As your mind begins to clear and you start to come out of your psychotic episode now is the time to take on your role as case manager. By monitoring your condition regularly you will be able to assess your symptoms and feed this back to your doctor. This data can then be used by both of you to assess the severity of your condition at the time and work out the optimum therapeutic dose of the best medication for you.

Talking Therapy

There are many different types of talking therapies available today that can help in cases of schizophrenia including counselling, support groups and psychotherapy. Talking therapy is the second element in this strategy and after medication it is the most important component of getting well. Research has shown that people with schizophrenia who get regular talking therapy are more likely to take their medication and will have fewer relapses.⁶ However remember that although talking therapy is extremely beneficial when used in combination with medication, there is no evidence that it can be used to treat schizophrenia on its own.

Like medication the talking therapy has a beneficial "dose". There will be times when, if you are very unwell and totally lacking in insight talking therapy may be of no benefit at all because of your very low level of understanding. Then as you begin to come out of the psychotic episode you may need quite a high level of therapy such as weekly counselling and support groups. Later, when you are feeling much better and are better able to cope you can revert back to a "maintenance dose" of perhaps monthly counselling and support group.



For people with schizophrenia a weekly session with a good counsellor will help you to explore your problems and cope better (Image:Monkey Business Images/Shutterstock)

Counselling

Counselling will be an important component in your talking therapy regime. Counselling involves meeting a trained counsellor, face-to-face, periodically for a private discussion. Each session usually lasts about an hour. The discussion can cover any subject that is important to you at the time. Counsellors do not usually try to make suggestions but rather to guide and support you in finding your own solutions.

There are many organisations across the country who provide counselling free of charge or at a nominal fee for people who are on benefits. In some areas counselling can be obtained at your GP's practice. If this service isn't available in your area then you may need to see a counsellor privately. Typically rates for an

hour's private counselling session are £30 to £50. If you find the cost of this prohibitive then try applying for the Personal Independence Payment which is a government payment designed to help people with health problems provide these sorts of services for themselves.

If you can find someone who can recommend a good counsellor then that is a good way of finding one but you may have to try out a couple of counsellors before you find one you can work with. You can also ask at your GP's practice or at one of the centres run by the mental health charities like Mind or Rethink. Counsellors can also be found on the internet or by asking at your local reference library. Finding and choosing a good counsellor is one of the most important roles you have as your own case manager.

Remember that your relationship with your counsellor is a confidential one. The only time that they would think of disclosing anything about a counselling session to your doctor is if they think that you were at risk of hurting yourself or somebody else.

Before you go to your counselling session try to spend a little time thinking about any issues that you would like to talk about with the counsellor. Remember that you are taking on the role of your own case manager now and it is your role to identify and deal with important issues as they arise in your life. For instance you may feel that you need help in improving your self esteem, coping with family relationships or better understanding things that have happened in your past. Now is your opportunity to address them.

When the counselling session is over it is a good idea to sit quietly with a coffee and reflect on what was discussed. Make a few notes in a notebook about any issues that the session raised that you might want to come back to later. You can then refer to your notes during the week and try to work on these issue more in your own time.



Support groups can help as they give you the chance to meet other people with schizophrenia who have similar problems (Image mangostock/Shutterstock)

Support Groups

Support groups can also be invaluable in the early stages of your recovery. They are often run by organisations such as Mind or Rethink or by some NHS organisations. A support group is a meeting of a group of people, who have the same kinds of experiences of mental health issues as you, for a group discussion which can last usually between one and two hours. Sometimes there is a break for refreshments.

The support group will usually concentrate on a particular issue such as hearing voices or anger management although the discussion may widen to cover general aspects of day to day life for the

members. The discussion is led by a facilitator and there are usually a set of group rules covering issues like confidentiality and respect.

Without a doubt a good support group can be extremely beneficial. It will give you the opportunity to meet with other people who have similar experiences to yours such as hearing voices and to talk about how those experiences have affected you and how you have coped with them. It will also give you the chance to talk about problems with everyday life such as benefits and housing. Here's what one sufferer said about his hearing voices group at the local Mind centre:

"An important milestone in my recovery came when I discovered the Hearing Voices group at Mind. I began attending the Hearing Voices Group in the spring of 2002. It gave me the opportunity to meet with other people who had also had psychotic experiences: some similar to mine but others unique to themselves. By learning that other people had these experiences as a result of mental illness, the belief that had been developing for several months that I was ill was reinforced and I was finally given the confidence that I needed to go back to the doctor and reveal the full extent of the secret turmoil that my mind had been in. He arranged for me to meet the psychiatrist and I was finally diagnosed with schizophrenia.

The group also provided me with support on a personal level. From week to week we discuss how we are, how we are feeling, how our voices have been and what other psychotic experiences may have been giving us problems. We talk about problems with medication, with doctors and CPNs, with benefits and housing, with neighbours and family. The ethos is always supportive, never confrontational and the emphasis is on helping members to cope with or manage their voices and other experiences which are often, despite their medication, still a painful part of their life."

But, a word of caution here: support groups do tend to reflect the views of their membership which can change over time and even from week to week. In addition they are often facilitated by volunteers with varying levels of training. They can vary greatly from group to group and from week to week so don't worry if you don't get much out of your first visit, keep trying and if over time you don't find the group useful then it may be best to look for another group.

Useful Occupation

At all stages of the illness it is vital to be able to occupy your time. This will help to distract you from your mad thoughts and will enable you to relax better. However the type of occupation that you can cope with will vary with the stage of the illness. For some people suffering with psychosis, beliefs that TV and radio programmes or books are sending them messages can sometimes make those activities risky. This is what psychiatrists call ideas of reference and it can be one of the most isolating experiences for people with schizophrenia since it shuts them off from any meaningful interaction with the world about them.



At first it is vital to find some simple form of occupation like gardening that won't feed the psychotic thinking (Image: Alexander Rath/Shutterstock)

The key is to find an activity that does not seem to provoke the mad thoughts. This will vary from individual to individual. When your condition is very severe you may only be able to cope with very simple activities such as jigsaw puzzles or a little light gardening or a quiet walk in the country. Whether you are best able to do it on your own or whether you would prefer to be with someone else is very much a question of personal choice.



As you start to come out of the psychotic haze group activities like the TCV's Green Gym can help

Later on as your mind begins to clear you can be more ambitious perhaps joining an art therapy or music therapy class such as the ones run by branches of Mind and Rethink. You might take up a sport or join a gym. Physical activities will help you relax and improve your sleep pattern and also help you to cope with weight gain if that is a problem caused by your medication. Some organisations such as The British Trust for Conservation Volunteers (<http://www.tcv.org.uk/>) organise conservation activities in the countryside where you can work off a few pounds, meet new friends and do valuable work for the environment.



Rufus May a British psychologist who suffered and recovered from schizophrenia

Here's what Rufus May who suffered an episode of psychosis and recovered to become a well know clinical psychologist said about the role of useful occupation in his recovery:

*"Drama and later dance were helpful therapeutic activities. Both helped me express my emotions in a socially acceptable way. From my initial breakdown I began to systematically avoid social contexts where I was not valued. This helped me rebuild my confidence and my sense of others having confidence in me."*⁷

Later on when your condition has much improved and you are at the stage when you are beginning to discuss reducing the dose of medication and talking therapy with your doctor it may be time to start to

think about a foray into employment or study.

Your local Council for Voluntary Service and your local reference library will be able to give you information about opportunities for doing voluntary work in your area. Or you may feel that it is time to look at returning to paid work on a part time basis. Opportunities for study either part time or full time are also available through your local WEA or further education college. If you don't feel up to the structure that study would require then perhaps you would benefit from studying at home by a distance learning course. See our information sheets on employment and volunteering for more ideas.

Family and Friends

Without a doubt supportive family and friends are of great benefit during a period of serious mental ill health. There are a number of benefits of having a sympathetic and compassionate circle of close friends and family around you at this time of crisis. They can provide you with a roof over your head, emotional support, support in dealing with doctors and courts, and help in dealing with your financial affairs. However don't expect miracles from your family. Very few people have any training or experience in coping with serious mental health problems. Your loved ones will have to learn this new role as they go along so you need to be able to forgive them if they don't get it all right first time.

Having a roof over your head during a period of mental ill health is key. Living on the streets or "sofa surfing" will ensure that you don't have access to the help that you need. For your mental health such a situation is potentially disastrous.



If you are living with your parents it is important to try to talk to them to share your problems and involve them in your struggle

If you do have the good fortune to be living with your parents or with a partner then you must recognise the enormous benefit that that situation gives you and do everything you can to live cooperatively with them. This may not always be easy. It may be difficult to communicate with your loved one because you are getting strange hidden messages in everything that they say to you. Activities that you used to enjoy together such as watching the TV may be difficult because you are getting secret messages from the programmes or because you are hearing voices. They may find that you are difficult to get on with or have become very withdrawn. You may want to stay up all night when they want to go to bed. Whatever the difficulties it is important to find a way of living together that you can both cope with.



If you are living at home it is important to help with your share of the chores (Image: Africa Studio/Shutterstock)

This may involve some negotiation to ensure that you do not do anything that disrupts the family life. In addition it is important to realise that every member of the family needs to contribute. If your parents or partner are working to provide you with somewhere to live then you need to do your fair share of the household chores.

One of the first effects of intense psychosis is that you will stop looking after your financial affairs. You may not be able to work and may be unable or unwilling to claim benefits. Bills will go unpaid and threatening letters from creditors will build up. Creditors may take court action against you and you may end up with black marks on your credit record. Having a close family member or friend who can look after these aspects of your life when you can't is invaluable. Problems with court judgements or worse still bankruptcy proceedings will come back to haunt you later in life and are best avoided at all costs. Sadly many people who experience schizophrenia end up with a burden of debt and poor credit history that takes many years to shed.



Managing your finances well is vital as a poor credit record may well stay with you for years to come. (Photo: Andrey_Popov on Shutterstock)

When you are fully recovered it may be a good idea to think about making an Advanced Statement or Power of Attorney to enable someone else to look after your affairs if you should relapse in the future.

As your condition improves your family will find it very helpful to their understanding of your condition if

you can share with them the details of some of your experiences. Tell them about the voices or other hallucinations or tell them about the strange beliefs that you developed. Explain to them how the mad thoughts and ideas that you had while you were psychotic affected the way that you behaved towards them.

You should also try to describe some of the problems to your close friends as well but be very careful about disclosing details. For the time being your friends probably don't need to be told about your diagnosis or the details of your mad thoughts but explaining to them that you have had a breakdown may be well useful in helping them to understand what you have been through. This is a sensitive area and it is covered in more detail in our information sheet on disclosure. Disclosing too much too early to friends can be counterproductive but getting the disclosure angle just right can help get them on your side.

However not everyone is fortunate to have supportive family and friends. Whereas having a supportive circle of family and friends is of great benefit it may be that some of your family and friends may not react as positively. If you have family or friends that are unsupportive or even hostile it is important not to be judgemental about them. Very few people have much awareness of this very disruptive condition that we call schizophrenia and it often comes as an enormous shock when they find that their loved one is behaving strangely especially if your behaviour is very disruptive and the police or courts have been involved. In addition some people find it difficult to cope with mental ill health in others because they themselves have had mental health problems in their own life.

Sadly you may find that some of your closest family and friends will reject you at the time that you most need their help and this will be a bitter pill to swallow indeed. However, although losing friends and family is a painful process it is often in this case a necessary one. For the future you will need people around you who will be able to react promptly and constructively in the event that you experience a relapse and it is important to have around you a circle of people who will be able to respond well and get you the help you need. The members of your family or friends who have rejected you now will probably not be best suited to that role in the future and it may be best to leave them behind however painful it may be.

Rest and Relaxation

Getting enough rest and relaxation is an absolutely key element of the I'M TUFRR strategy. Very often episodes of schizophrenia are associated with periods of frenetic activity while you attempt to satisfy the incessant demands of your mad thoughts. As you begin to come down from the psychotic "high" you will need to re-learn how to relax.

Alternatively the negative symptoms of schizophrenia may have made you withdrawn and lethargic and you may find it very difficult to become active again in which case learning to chill out won't be an issue for you but learning to structure your life to find an appropriate place for your chill out time will be essential. The aim of the strategy is to make sure that you get enough time in your life to relax but not too much.



Try to set aside part of your week for just chilling with no arrangements or jobs to do (Image: Mooshny/Shutterstock)

Try to aim to have a specific day each week for chilling out. Sunday is a good day since other people around you will be doing the same. Avoid making any arrangements for this day and reserve it for relaxing activities such as watching TV, reading, 'phoning family and friends, napping and taking light walks. These activities can be done on your own or with someone else depending on which you find more relaxing. Try to make this a day when you have no commitments and are free to do as you please. It is a good idea to start the day with a lie in if you are an early riser.

When you have got into a routine with your chill out day then try to set aside another day for your domestic jobs such as doing the weekly shop, cleaning house, laundry etc. If you do your domestic chores and your relaxing at the weekend rather than during the week you will be introducing the all important structure into your life. On weekdays you can attend your appointments, support groups, counselling etc and then keep the weekends free for your personal self-maintenance, to rest and recharge your batteries for the week ahead.

In this way when you do return to work or formal study you will already have developed a structured life style that will support your activities. One of the things that many people who return to work after a long break find difficult is how to fit in all of their personal commitments into the reduced free time that they have available. Structuring your week will help you prepare better for this stage.

It is important not to neglect your domestic chores. Learning to look after yourself and your home is one of the big milestones of your recovery. However don't overdo it. Don't become so meticulous about keeping your place clean that you have no time left for anything else. Work out how much time you need to spend on domestic chores each week and stick to it. If you are living with parents or a partner it would be a good idea to discuss this with them before you start then you can work out between you what the priorities are. This would also be a good time to discuss with them your plan to have a day a week set aside for relaxing and that you would prefer not to have any arrangements on that day.

Whilst it would be a useful aim to organise your domestic chores and relaxation time around a two day weekend period it may be that you need more time for relaxation especially in the early stages of your recovery. At this point you may need a three or even four day weekend with perhaps two days for chilling out.

WRAP

So I'M TUFRR is one strategy for recovery but it's not the only one. WRAP is another strategy that you may find suits you better.⁸



Mary Ellen Copeland, inventor of the Wellness Recovery Action Plan system for coping with mental ill health (Photo: WRAP)

WRAP or the Wellness Recovery Action Plan was developed in the US but is now widely used in the UK as well. It is a structured system for monitoring your condition during periods that you are unwell or are becoming unwell and coping with those periods using responses that you have planned in advance during times that you were much better. The plan has five sections.

Section one is a daily maintenance plan which looks at the things that you need to do in your daily life to help you stay well. It also involves monitoring the thoughts and feelings that you have while you are well and that you associate with being well so that you will be able to spot when things are changing.

The plan suggests using descriptive terms to assess your degree of wellness such as bright, cheerful or happy.

Section two is about recognising the triggers that may cause you to become unwell. These are what psychiatrists in the UK often call precipitating factors. Triggers are external factors that happen in our lives such as family friction or stress at work rather than internal thoughts and feelings.

The WRAP strategy recommends having a series of pre-planned responses to triggers such as talking to a counsellor or working through some of the negative thinking patterns.



Spotting early warning signs like craving alcohol or street drugs is key to the WRAP strategy
(Image:Shutterstock)

The next part of the WRAP strategy is to look for early warning signs of the onset of a period of ill health. Some early warning signs may be quite minor such as buying things you don't need or becoming forgetful, whereas others could be more significant such as craving alcohol or street drugs. Whether the signs are significant or minor, they serve to ring alarm bells about a deterioration in your condition.

Part four of the WRAP strategy is to identify when things are breaking down. We all know that there are times when no matter how hard we try our condition seems to get worse and it is important to be able to spot the signs of that stage. Here the warning signs may be quite significant such as sleeping continuously or not at all, or having thoughts of suicide or self harm.

At this point it is necessary to activate your personal plan which will almost certainly involve getting professional help from your health care workers such as GP, psychiatrist or Community Psychiatric Nurse.

Next WRAP takes us to crisis planning. This involves giving advanced advice to those around you about what you are like when you are well and then move on to describe the changes that will take place as you become unwell. Then describe the things that worked well for you when you were last unwell such as the types of medication that were effective and what kinds of therapies you found helpful.

Make a list of supporters who can help you when you are in crisis and describe the sorts of things that you will need help with.

The final part of the WRAP strategy is optional and it is the post-recovery plan which will help you to cope with the time when you are recovering and are coming off the very high level of support you may have had during the crisis.

One thing that is fundamental to the WRAP strategy is the need to educate yourself about your condition:

"When dealing with mental health challenges in your own life, educate yourself about the possible causes of these issues, and what can be done to relieve and eliminate them. In order to make good decisions, it's important to find the answers to key questions that could affect your wellness, your recovery, and your life". Mary Ellen Copeland

Conclusion

Recovery from schizophrenia is possible for a large proportion of those diagnosed. However recovery is not easy: it is a gruelling and often lengthy path that requires immense effort on the part of the sufferer and their relatives and carers. It is essential for people living with schizophrenia to take some responsibility for their recovery and to take a lead role in managing it. Having a strategy to help you in this struggle is vital.

References

1. Jones S and Hayward P, 2004, Coping with Schizophrenia, One World Publications, p10.
2. Fuller Torrey E, 2001, Surviving Schizophrenia, Quill, p130.
3. Howe G, 1997, Serious Mental Illness - A Family Affair, Sheldon Press, p72.
4. Author's personal experiences.

5. Fuller Torrey E, 2001, Surviving Schizophrenia, Quill, p212.
6. Snyder K, 2007, Me, Myself and Them, Oxford University Press, p96.
7. May R., December 2000, Routes to recovery from psychosis: the roots of a clinical psychologist, Clinical Psychology Forum, p8.
8. Copeland M E, 1997, Wellness Recovery Action Plan, Peach Press.
9. The section on the I'M TUFR strategy is based on the author's personal experiences.

Links

<http://www.mentalhealthrecovery.com/wrap/>

<http://www.mind.org.uk/>

<http://www.rethink.org/>

<http://www.tcv.org.uk/>