Getting Well, Staying Well
A handbook for understanding relapse for people with schizophrenia and bipolar disorder, and their carers

The Think Twice initiative has been developed in partnership with Lilly UK, which has also provided funding
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SANE and Lilly UK would like to thank the following healthcare professionals who have contributed their time, experience and expertise to help develop this handbook:

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- **Ian Hulatt**, *Mental Health Advisor at the Royal College of Nursing*, Cardiff
- **Professor Martin Knapp**, *Professor of Social Policy and Chair of LSE Health and Social Care; Professor of Health Economics and Director of the Centre for the Economics of Mental Health at the Institute of Psychiatry, King’s College, London*
- **Dr Jill Rasmussen**, *GPSI East Surrey PCT and Moat House Clinic, Surrey*
- **Elaine Weston**, *Chief Pharmacist, Leeds Mental Health NHS Teaching Trust, Leeds*
About Think Twice

The Think Twice campaign aims to encourage people with schizophrenia and bipolar disorder, those who care for them, and healthcare professionals to think again about relapse. Thinking twice about relapse means considering not only why relapse occurs, but what ‘being well’ means to people with schizophrenia and bipolar disorder and the impact relapse has on them and the people around them. Importantly, thinking twice is about looking at how schizophrenia and bipolar disorder are managed in the long term to reduce the chance of a relapse so people can get well and stay well. The Think Twice campaign, launched by SANE, has been developed in partnership with Lilly UK, which has funded the production of this handbook and also a companion guide specifically for healthcare professionals.

About this handbook

This handbook provides information and advice about getting well and staying well for people with schizophrenia and bipolar disorder, and those who care for them. To ensure its relevance and usefulness, SANE asked over 100 people with either schizophrenia, schizo-affective disorder and bipolar disorder about their experience of relapse1. Additionally, information from a survey of carers (family members and friends) was also used to help provide a carer’s perspective2. By letting the people who really matter – people just like you – share their thoughts, it is hoped that this handbook will provide you, or the person you care for, with the information you need about relapse prevention.

Throughout the handbook you will see thought bubbles like this one which contain questions

These questions are designed to provide you, or the person you care for, with an opportunity to think about your own experiences. So that an action plan can be developed based on individual needs, you might like to discuss the answers to these questions with your mental health team. To help you do this, included in the back of this handbook is a fold-out information card, which has been specifically designed to help you identify the personal factors that may contribute to a relapse or signs that a relapse might be occurring. Additionally, it provides details of appropriate support networks you can access should you, or the person you care for, feel you may be in danger of experiencing a relapse.

Before you continue...

Thinking about your condition, or that of the person you care for, may at times lead to thoughts or emotions that you find difficult to deal with. If you feel distressed you can call SANELINE on 0845 767 8000 (calls charged at the local rate). SANELINE is open everyday between the hours of 1pm and 11pm.
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"Relapse can have devastating consequences for people with schizophrenia and bipolar disorder, as well as for their friends, family and carers. SANE hopes the Think Twice campaign will bring to the forefront of people’s minds the scale of the problem and help educate them on how to reduce the risk of a relapse. By giving people information and practical advice to understand their condition, we hope they will be able to live productive and healthy lives.”

Marjorie Wallace, Chief Executive of SANE

Understanding Relapse

If you, or the person you care for, has experienced a relapse, you are not alone. Of those surveyed, almost seven out of 10 people had experienced at least one relapse during the course of their illness. Many people had experienced more than one. Furthermore, of those who had experienced a relapse, 93% said they worried periodically about possible future relapse.

Experiencing a relapse can be distressing for the individual concerned, and those around them. It can make integrating into society difficult and threaten the ability of people living with schizophrenia and bipolar disorder to function independently in day-to-day life, engage in a hobby, have an active social life or hold a steady job. It may be possible to reduce the chance of relapse occurring by learning more about the warning signs of relapse and the events that can lead up to it.

"Preventing relapse is the most important goal in the long-term management of schizophrenia and bipolar disorder. Discussing relapse prevention with your mental health team should be a priority for those living with schizophrenia and bipolar disorder.”

Dr Richard Hodgson, Consultant General Adult Psychiatrist, Staffordshire

What is relapse?

By ‘relapse’ we mean any worsening of symptoms associated with schizophrenia and bipolar disorder after a period of feeling better or more mentally stable.

People living with bipolar disorder may experience a return to the manic phase of the condition where they feel ‘on a high’ or are overly excitable and euphoric. They may also experience delusions and can lose insight into their condition, leading them to deny that there is anything wrong. A relapse into
the depressive phase can often lead to difficulty coping with day-to-day activities and can involve feelings of unhappiness and hopelessness that may develop into thoughts of suicide³.

For people living with schizophrenia, a relapse may mean that they experience a recurrence of delusions, hallucinations or unusual thoughts, beliefs and experiences. They may also have disorganised speech or thinking, causing them to lose track of conversations, or chaotic and confused behaviour often manifesting itself in extreme agitation⁴.

Why does relapse occur?

As each person’s experience of schizophrenia and bipolar disorder will be different, there may be many different reasons for relapse occurring.

The main reasons for relapse (relapse triggers), as identified by those surveyed, were stressful life events and stopping medication.

The table below shows the triggers most commonly reported by people in the Think Twice survey:

<table>
<thead>
<tr>
<th>Factor</th>
<th>Percentage of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stressful life events</td>
<td>56%</td>
</tr>
<tr>
<td>Stopping medication</td>
<td>26%</td>
</tr>
<tr>
<td>Physical ill health</td>
<td>19%</td>
</tr>
<tr>
<td>Time of year</td>
<td>18%</td>
</tr>
<tr>
<td>Alcohol or drug abuse</td>
<td>16%</td>
</tr>
<tr>
<td>Reduction in services</td>
<td>14%</td>
</tr>
<tr>
<td>Medication stopped working</td>
<td>11%</td>
</tr>
<tr>
<td>Change in medication</td>
<td>10%</td>
</tr>
<tr>
<td>Talking therapy discontinued</td>
<td>6%</td>
</tr>
</tbody>
</table>

“Identifying relapse triggers is one of the key steps people can take to minimise the chance of a relapse. Your mental health team is ideally placed to help you identify your triggers and develop ways for keeping well.”

Dr Jill Rasmussen, GP, Surrey
Just over half of those surveyed felt that stressful life events such as bereavement, debt, bullying, loss of a job, moving house or relationship problems contributed to their relapse. You may be able to think of similar events that you, or the person you care for, find stressful and have led to a relapse in the past. Your psychiatrist, GP or community psychiatric nurse will be able to help you, or the person you care for, develop strategies to cope with stressful life events.

Another common reason for relapse is that people stop taking their medication. Discontinuing treatment increases the risk of relapse by almost five times\(^5\) and 88 per cent of carers surveyed felt that stopping medication had contributed to a relapse. The survey also revealed many different reasons why people stopped taking their medication, including experiencing unwanted side-effects, feeling better and thinking medication was no longer needed, or thinking that medication was not working.

**Question:**
What are my relapse triggers?
**Being Well**

Being well means different things to different people. This is what it meant to the people who took part in the *Think Twice* survey:

<table>
<thead>
<tr>
<th>Feature of well-being</th>
<th>Percentage of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to trust my own thoughts</td>
<td>44%</td>
</tr>
<tr>
<td>Able to function independently in day-to-day life</td>
<td>37%</td>
</tr>
<tr>
<td>Feel alert and alive</td>
<td>36%</td>
</tr>
<tr>
<td>Feel hopeful about the future</td>
<td>32%</td>
</tr>
<tr>
<td>Able to have an active social life/maintain relationships successfully</td>
<td>27%</td>
</tr>
<tr>
<td>Able to hold a steady job/volunteer</td>
<td>25%</td>
</tr>
<tr>
<td>Able to stay out of hospital</td>
<td>24%</td>
</tr>
<tr>
<td>Not having delusions/hallucinations</td>
<td>24%</td>
</tr>
<tr>
<td>Balance between side-effects of medication and symptoms</td>
<td>16%</td>
</tr>
<tr>
<td>Able to enjoy the environment</td>
<td>9%</td>
</tr>
<tr>
<td>Able to learn a new skill and attend a class</td>
<td>8%</td>
</tr>
<tr>
<td>Able to engage in a hobby</td>
<td>4%</td>
</tr>
</tbody>
</table>

In addition to these factors, when you are well it means that you are able to become involved in managing your own physical well-being, including eating healthily, taking exercise or visiting the doctor regularly for health check-ups. Furthermore, in the survey of carers it was found that when their family member was well they experienced less stress and tension and there was an increase in quality time spent as a family.

“For me, being well has enabled me to get back in contact with my family after losing contact with them for a number of years. I am also able to apply for jobs, something I never thought would be possible.”

Clive, 45, has lived with schizophrenia for over 10 years
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Recognising Relapse

Despite taking preventative measures, you or the person you care for may still experience a relapse. For many, the prospect of relapsing may cause feelings of depression, sadness, hopelessness or despair. Others may experience feelings of fear, anger, resentment or disappointment. Whilst these are common feelings, it is important not to think that you have failed if you feel you are going to relapse, but seek help as soon as possible. By recognising the early indicators of relapse and having pre-planned steps in place to ensure that you or the person you care for get help at an early stage, it is possible to reverse the relapse process and take back control of your well-being.

It can sometimes be difficult to recognise the signs of relapse, but common early signs cited in the *Think Twice* survey included:

- **Changes in thinking** – such as a gradual return of paranoid or delusional ways of thinking, racing thoughts or obsessive thought patterns. Some people also experienced an increase in their intellectual or creative abilities.

- **Changes in sleeping patterns** – for example, difficulty sleeping and feeling tired.

- **Changes in mood** – often a lowering of mood or feelings of anxiety, fearfulness or panic but sometimes also elation, enthusiasm or uncharacteristic confidence.

- **Withdrawing from contact with other people**

- **Changes in behaviour** – such as a tendency to behave in an obsessive, ritualistic or uninhibited way.

- **Feeling distracted** – difficulty concentrating on everyday tasks.

Although you may recognise some of these signs, each person’s experience of relapse is different. The early indicators of relapse that you, or the person you care for, may experience will be unique and this is known as your **relapse signature**. Your relapse signature is something that can be worked out in conversation with your mental health team, family, friends or carer.

Part of the process involved in recognising relapse is being familiar with how you, or the person you care for, think, feel and behave when well. By attempting to keep this in focus, you can start to identify changes in thinking, mood and behaviour that indicate a slide towards relapse.

**Question:**
What is my relapse signature?
Pulling Through a Relapse

There are many factors that can help people recover effectively from a relapse. The Think Twice survey found that the most important factors which people felt had helped them pull through a relapse were:

- A prompt initial reaction from a doctor, community psychiatric nurse or support worker
- Sustained and regular contact with a doctor, community psychiatric nurse or support worker
- Support from family and friends
- Medication
- Access to talking therapy
- Hospital care

However, each person’s experience of relapse is different and there may be other factors that you find helpful in becoming well again. Learning from each relapse will help you, or the person you care for, to understand the triggers and the early indicators of relapse better so that help can be sought at an early stage.

“Experiencing a relapse is undoubtedly an anxious time for those affected, their carers and families. It is vital that individuals are supported and effectively enabled to restore order to their lives. Mental health nurses are well placed to facilitate this by the nature of their ongoing relationships with all parties involved. However, a critical factor is the open discussion of what a relapse looks and feels like and for everyone involved to be aware of how it occurs.”

Ian Hulatt, Mental Health Advisor at the Royal College of Nursing, Cardiff
Minimising the Chance of Relapse

You may find it helpful to think about your condition, or the condition of the person you care for, as a vulnerability to episodes of illness (relapse) rather than as something that is constantly present. The treatments and approaches for reducing the chance of relapse that are talked about below and elsewhere in this handbook are designed to reduce that vulnerability.

Understanding your condition

When asked about the factors perceived to be important in keeping well, those surveyed scored “understanding my illness, its symptoms and my medication” highest. Accessing information about schizophrenia and bipolar disorder can help you, or the person you care for, to understand and recognise the potential triggers and indicators of relapse and the treatment options available. Information about schizophrenia and bipolar disorder can be obtained from your mental health team or from support groups such as SANE.

Finding the right treatment

Because everybody’s experience of schizophrenia and bipolar disorder is different, treatments will also vary from person to person.

- Medication

Medication is the most common form of ongoing treatment and one that many people find gives them the greatest improvement in their condition. It can help manage or alleviate symptoms and lead to a better quality of life. Many different types of medications are available and your psychiatrist will want to prescribe the one that is most likely to bring your symptoms under control the quickest, whilst minimising side-effects. In addition, they will need to think about minimising the chance of future relapses from the outset.

It is not uncommon for people to have difficulty in finding a suitable medication. The Think Twice survey found that nearly half of participants had tried between two and five different medications before finding one that led to long-term improvement in their condition and well-being. It is important you find the best medication for you, or the person you care for. Ask your psychiatrist or pharmacist to discuss your treatment choices with you.
People need to understand the benefits and have confidence in their medication. People should feel able to discuss medication choice with their mental health team so they have all the information they need.”

Elaine Weston, Chief Pharmacist, Leeds Mental Health NHS Teaching Trust

Stopping medication can increase the chance of relapse so it is important not to stop taking your treatment without speaking to your mental health team. The Think Twice survey revealed that there are many reasons why people stop taking their medication, some of which you, or the person you care for, might be able to relate to:

<table>
<thead>
<tr>
<th>Reasons for stopping medication</th>
<th>Percentage of participants*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side-effects</td>
<td>57%</td>
</tr>
<tr>
<td>Feeling well and thinking medication was not needed</td>
<td>40%</td>
</tr>
<tr>
<td>Thinking that medication was not working</td>
<td>40%</td>
</tr>
<tr>
<td>Being upset about having to take medication</td>
<td>37%</td>
</tr>
<tr>
<td>Forgetting to take the medication</td>
<td>36%</td>
</tr>
<tr>
<td>Dislike of stigma around taking medication</td>
<td>23%</td>
</tr>
</tbody>
</table>

*Who had stopped taking their medication

The occurrence of unwanted side-effects is a common reason for people to stop taking their medication. It is also important to remember that even if you feel well and your symptoms are under control you shouldn’t stop taking your medication without consulting your psychiatrist or pharmacist.
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“I was terrified because I had never heard of bipolar disorder and didn’t know what to expect. I was prescribed medication which made me feel better and I was discharged from hospital. Because the symptoms went away I thought it meant I was cured and so I decided to stop taking my medication. This led to my symptoms reappearing and eventually I had to be readmitted to hospital. I now realise that feeling well is not the same as being cured and I have to keep taking my medication to stay well. Understanding my condition and medication, together with fantastic support from my community psychiatric nurse and support group, has allowed me to take back control of my life.”

Celia, 45, diagnosed with bipolar disorder 5 years ago

Many people stop taking their medication because they feel it is not working. Of those surveyed, 40 per cent of those who had stopped taking their medication reported this as a reason for discontinuing treatment. If you are concerned about the medication you are taking, you should make an appointment to talk to your psychiatrist, GP or community psychiatric nurse before stopping treatment.

- Talking therapy
  Talking therapies such as psychotherapy, counselling and cognitive behavioural therapy can help people living with schizophrenia and bipolar disorder. They can provide emotional support and enable people to recognise problems, develop coping strategies and learn how to prevent crisis situations from developing.

- Group therapy
  Many people find it helpful to share their own experiences with people who understand what they are going through. It can also help you to learn from other people who have had similar experiences. Group therapy typically involves between six and ten individuals meeting face-to-face with a trained group therapist to discuss their feelings, try out new ways of behaving and learn more about the way they interact with others.

Stress management
Reducing exposure to stressful events through lifestyle choices or implementing coping methods to allow you to deal with stressful situations can help minimise the chance of a relapse. You can develop strategies for managing your emotions and so combat the mood changes that often occur before a relapse and as a consequence of stressful life events. It is important not to worry excessively about the possibility of relapsing, as this in itself can
lead to stress. Being prepared and aware of steps to minimise the chance of relapse can be one of the best ways to reduce the worry associated with the prospect of relapse. Ask your mental health team about self-help resources for managing stress.

**Talk to your mental health team**

Keeping your mental health team, which can include your psychiatrist, community psychiatric nurse, GP, practice nurse and pharmacist, informed about how you are feeling and whether your medication or other therapies are working for you is a good way of helping to manage your own condition. They will be able to provide you with the information and support you need and help you to put in place steps that can enable you to better look after yourself.

If you are concerned about any deterioration in your health, or that of the person you care for, you should immediately alert your psychiatrist, GP or mental health team in order to avoid the possibility of a major relapse.

> "Talking to your mental health team about your medication can help you understand more about the benefits of your treatment and address any concerns you might have. By speaking to your mental health team they can work with you to identify a treatment that will be most effective in preventing relapse."

Dr Richard Hodgson, Consultant General Adult Psychiatrist, Staffordshire

**Seek support**

Participants in the *Think Twice* survey recognised the value of friends and family in providing support and helpful advice when they realised that they were becoming unwell. It is often friends or family who first notice someone is having a relapse, rather than the person experiencing the relapse themselves.

If you have schizophrenia or bipolar disorder, you may find it helpful to talk to your family and friends about your condition. They may be able to provide emotional and practical support, help you to identify signs of relapse, or attend medical appointments with you and become involved in developing treatment plans.

However, many people living with schizophrenia and bipolar disorder find it difficult to talk about their mental health with friends or family. Joining a support group can offer opportunities to share experiences with people who understand how you are feeling. They can also help you to learn from other
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people, provide you with information about your condition and above all help you realise that you are not alone in how you are feeling. To find details of your nearest support group, you can contact SANE.

Caring for your physical health

As part of managing your condition it is important that you look after your physical health. One in five participants in the Think Twice survey felt that physical ill health was a contributing factor to their last relapse.

It is important to eat properly by reducing the amount of fatty foods, for example, crisps, cakes and chocolate, and increasing the intake of fruit and vegetables in your diet, and to take regular exercise such as walking or swimming. This will help to make you feel better, increase your self-esteem and improve your physical health. It is also important to recognise the impact smoking, alcohol abuse and drug taking can have on your well-being. One in six of those surveyed thought that alcohol and drug abuse was a trigger in their last relapse.

Your mental health team can offer you simple and easy-to-follow advice on how to improve your physical health and well-being, often through specifically designed programmes. You may also find it beneficial to investigate attending regular health checks with your GP. A recent study looking at the physical health of people enrolled in a well-being support programme found that 69 per cent of people had not received physical health checks before joining the programme and 76 per cent of carers surveyed said they were not aware that people with schizophrenia and bipolar disorder are more susceptible to physical illness. Regular physical health checks can ensure that any health problems are detected and appropriate treatment given.

Keeping busy

Regularly taking part in activities that you enjoy and find relaxing, such as a hobby or voluntary work, can help you to develop a productive and fulfilling daily routine which many people find reduces their chance of a relapse. However, it is important to be aware that undertaking too many activities, focusing too heavily on one topic, forgoing sleep in order to do more or asking too much of yourself can increase your vulnerability to relapse or signal a possible approaching episode.

Question: What steps would help me to stay well?
References

1. Think Twice service users' survey: survey of 108 people with schizophrenia, schizo-affective disorder and bipolar disorder conducted by SANE online at www.sane.org.uk and via telephone interviews during July and August 2006.

2. Keeping Care Complete survey: an international survey of carers from Australia, Canada, Germany, France, Italy, Spain, the United Kingdom and the United States developed by the World Federation for Mental Health and Eli Lilly and Company. The research was conducted by an independent market research company IPSOS, between 15th November 2005 and 6th April 2006. Data in this booklet comes from the UK arm of the survey of 100 carers.


Next steps

We hope you have found this handbook helpful and that it provides key advice and tips for staying well. The attached card provides a summary of the key information from this handbook and also provides space for you, or the person you care for, to include your own information and answers to the questions that have been highlighted throughout this guide. Together with your mental health team, you can use this tool to help develop strategies for dealing with relapse, to ensure you get well and stay well.
Further Help and Information

There are many support groups for those affected by schizophrenia and bipolar disorder. To find the one nearest you, visit the SANE website at www.sane.org.uk or call SANELINE on 0845 767 8000 (calls are charged at the local rate). SANELINE also offers emotional support, crisis care and detailed information to those experiencing mental health problems, their families and carers and is open from 1pm – 11pm every day of the year.

Although not directly supporting the Think Twice Campaign, other organisations able to offer support and help include:

Carers UK
Tel: 0808 808 7777 (open 10am-12pm and 2pm-4pm Wednesday and Thursday)
www.carersonline.org.uk

MDF – The Bipolar Organisation
Tel: 08456 340 540 (open 9am-5pm from Monday to Thursday and 9am-4pm on Friday)
www.mdf.org.uk

MIND
Tel: MindinfoLine 0845 766 0163
www.mind.org.uk

Rethink
Tel: 020 8974 6814 (open 10am-3pm, Monday to Friday)
E-mail: advice@rethink.org
www.rethink.org

Samaritans
Tel: 0845 7 90 90 90 (open 24 hours every day)
www.samaritans.org

Schizophrenia Association of Great Britain
Tel: 01248 354048
www.sagb.co.uk

ZY3445 October 2006
Who can I contact for support?

GP:

Community Psychiatric Nurse / Psychiatrist:

Social Worker:

Other:

SANELINE Tel: 0845 767 8000 Open 1pm - 11pm every day
www.sane.org.uk

Samaritans Tel: 0845 790 9090 Open 24 hours every day
www.samaritans.org

Important details

Name:

Diagnosis:

Nearest relative, including contact details:

Medication:
What can I achieve when I am well?

1. 
2. 
3. 
4. 
5.

What steps would help me to stay well?

- Understanding more about my condition
- Discussing treatment choice, including benefits and risks, with my mental health team
- Don’t stop taking my medication before speaking to my mental health team, even when I’m feeling better
- Maintaining good relationships with my friends and family
- Talking or group therapy
- Joining a support group
- Taking care of my physical health

Other suggestions:

What are my relapse triggers?

1. 
2. 
3. 
4. 
5.

What is my relapse signature?

1. 
2. 
3. 
4. 
5.