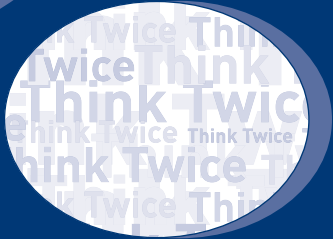


Getting Well, Staying Well

A companion to understanding relapse for healthcare professionals involved in the care of people with schizophrenia and bipolar disorder

A large, light blue oval graphic containing the words 'Think Twice' repeated in various sizes and orientations in a light blue font. The words are arranged in a way that they appear to be floating or overlapping.

Think Twice

A medium-sized, light blue oval graphic containing the words 'Think Twice' repeated in various sizes and orientations in a light blue font.

The *Think Twice* initiative has been developed in partnership with Lilly UK, which has also provided funding

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The *Think Twice* steering committee serves to ensure that the information provided as part of the campaign is accurate, balanced and relevant. As such, SANE and Lilly UK would like to thank the following who have contributed their time, experience and expertise to support the development of this healthcare professional guide and a separate handbook for service users and their carers:

- Dr Richard Hodgson, *Consultant General Adult Psychiatrist, Staffordshire*
- 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 the *Think Twice* handbooks

This handbook for healthcare professionals has been developed as a companion to a separate publication developed for patients and their carers. The complementary handbooks aim to support purposeful relationship-building and help facilitate open discussion about relapse in schizophrenia and bipolar disorder, between service users and healthcare professionals.

The service users' handbook *'Getting well, staying well: A handbook for understanding relapse for people with schizophrenia and bipolar disorder and their carers'* has been developed to help service users understand more about relapse and gain further insight into their condition. The handbook contains a detachable information card that is designed to act as a 'tool' for use with their healthcare professional to support the development of an action plan for recognising and, where possible, preventing relapse.



Copies of the service users' handbook are available to download at [www.thinktwicampaign.org](http://www.thinktwiccampaign.org). Hard copies can be requested via email: info@thinktwicampaign.org

About *Think Twice*

Think Twice is a campaign launched by SANE, developed in partnership with Lilly UK and supported by the *Think Twice* steering committee. It aims to encourage healthcare professionals, people with schizophrenia and bipolar disorder, and those who care for them, to think again about relapse.

The campaign draws together findings of research conducted specifically for *Think Twice*¹ amongst psychiatrists and people living with schizophrenia, schizo-affective disorder and bipolar disorder². It is supplemented by published studies, policy guidance and findings from an international carers' survey, *Keeping Care Complete*³, to create a renewed focus on the critical issue of relapse. By educating people, highlighting what can be done to minimise its impact and importantly by supporting service users in the long-term management of their condition, the campaign aims to help people living with schizophrenia and bipolar disorder get well and stay well.

Key Points

- Relapse prevention is one of the most important goals in the long-term management of schizophrenia and bipolar disorder.
- People with schizophrenia and bipolar disorder have a high risk of relapse and are likely to experience at least one during their life time.
- Relapse is distressing for the individual, their families and carers and has a negative impact on their quality of life and future prognosis. A large proportion of individuals constantly worry about, and fear the possibility of, future relapses.
- Using an effective treatment in the long-term will decrease the rate of discontinuation and prevent relapse. This is a key step in enabling people to function independently and avoid hospitalisation.
- Educating and engaging people to understand their illness, its symptoms and medication they are prescribed is crucial in keeping people well.

“When schizophrenia or bipolar disorder is diagnosed, the goal for healthcare providers is to stabilise the condition as quickly as possible so that well-being can be first restored and then maintained, to prevent relapse and ultimately eliminate the need for hospitalisation. However, this goal can be difficult to achieve and after an initial improvement, symptoms may worsen again leading to relapse, which can have devastating consequences for all those involved. By focusing more attention on relapse and facilitating informed dialogue about effective long-term care between service users, their carers and healthcare professionals we hope that the Think Twice campaign will provide valuable support in helping to minimise the chance of relapse”.

Think Twice steering committee

Introduction to Relapse

Relapse prevention is one of the most important goals in the long-term management of schizophrenia and bipolar disorder. However, acute episodes can unfortunately be a common experience. According to the American Psychiatric Association (APA), between 60 and 70% of individuals with schizophrenia, without maintenance treatment, relapse within a year and nearly 90% relapse within two years⁴. In line with this, 69% of people who completed the *Think Twice* service users' survey had experienced at least one relapse during the course of their illness and over half (58%) had experienced two or more relapses.

Every time a person with bipolar disorder or schizophrenia relapses, their future prognosis can be negatively impacted. Crucially, with each relapse it becomes more difficult to regain control of symptoms and return to the pre-relapse state⁵.

Of those psychiatrists surveyed, 74% felt that prompt initial response from a doctor, community psychiatric nurse (CPN) or support worker is the most important factor in getting patients well after relapse. However, this can only be achieved if people are able to recognise if and when relapse is occurring. Just over half of the service users surveyed who had experienced a relapse (60%) were able to tell ahead of time that they were going to relapse. Those that were able to predict their relapse were asked about the signs that helped them recognise they were about to get ill:

- **79%** noticed changes in their thinking
- **75%** noticed changes in their sleeping patterns, including difficulty sleeping and feeling tired
- **71%** noticed changes in their mood
- **63%** realised they were withdrawing from contact with others
- **46%** noticed other behavioural changes, including a tendency to behave in an obsessive, ritualistic or uninhibited way

Despite a high level of recognition of relapse, nearly one in six service user survey participants resident in the UK who had noticed a relapse approaching did not tell anyone about it. When people did tell someone, most commonly they contacted their psychiatrist (38%) or family and friends (38%), followed by their CPN (30%). Healthcare professionals therefore have a key role in acting quickly in response to fears of a relapse, and educating friends and family about recognising the indicators and the steps to take to ensure the person they care for receives prompt medical attention.

Impact of Relapse

■ Service users

According to the *Think Twice* service users' survey, of those who had experienced a relapse, 93% said they worried periodically about possible future relapse, with one in five saying they worried about it all the time. Fear was the most commonly cited emotion when thinking about the possibility of a future relapse, followed by anxiety, worry or apprehension. When thinking about their most recent relapse, service users most frequently felt depressed, hopeless and sad and many also experienced anger, resentment and disappointment.

For service users, the meaning of relapse goes beyond the technical description of a worsening of symptoms after a period of feeling better or more mentally stable. When relapse occurs it impacts on features they associate with 'being well' including their ability to trust their own thoughts (44%), function independently in their day-to-day life (37%) and ability to feel alert and alive (36%). These features of being well also allow them to achieve the following:

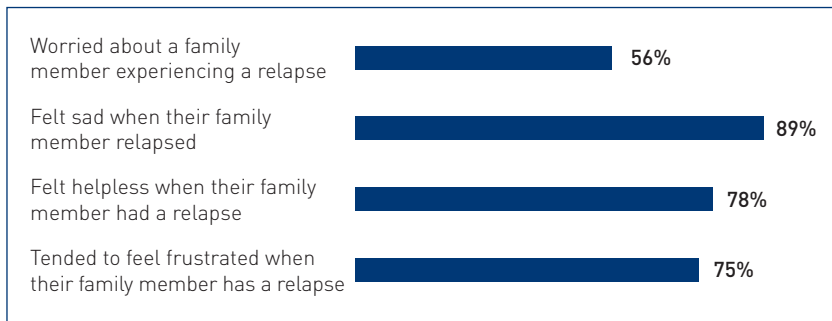
***Think Twice* service users' survey results: functional achievements whilst being well**

Achievement	Percentage of participants
Able to stay out of hospital	76%
Able to function independently in day-to-day life	69%
Able to engage in a hobby	61%
Able to have an active social life/maintain relationships successfully	55%
Able to hold a steady job/volunteer	50%
Able to learn a new skill and attend a class	50%

Results from the *Think Twice* service users' survey also highlighted the negative impact relapse has on the individual and their interactions within society, including their inability to work (83%), problems in relationships with friends and family (78%), self-destructive behaviour (74%), hospitalisation (61%) and trouble with the police (28%).

■ Carers

The stress created by caring for a person living with schizophrenia and bipolar disorder can be enormous. The *Keeping Care Complete* survey of carers revealed the significant emotional burden on carers as a result of a family member experiencing a relapse:



Managing the condition and avoiding relapse was found to create less stress and tension between family members, enabling an increase in the amount of quality time spent together as a family. The impact of relapse on carers can also have a financial cost: 5% of carers for people with schizophrenia reported having to stop work due to caring responsibilities. It has been calculated that this loss of productivity equates to as much as £27.5million.⁶

■ Healthcare professionals

Relapse also impacts on healthcare professionals, both primary and secondary care, in terms of workload and resources, as well as emotionally. When asked about their predominant feeling when one of their patients relapses, psychiatrists surveyed for *Think Twice* reported feeling concern for the patient's quality of life (53%) and frustration (23%).

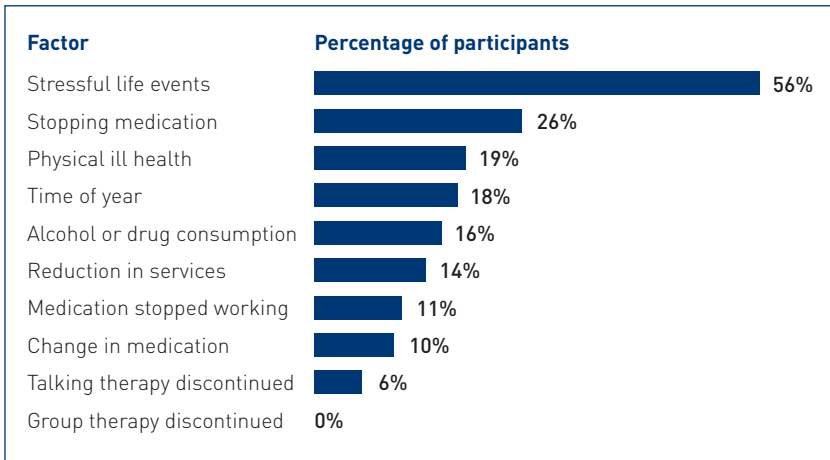
■ Healthcare system

Not surprisingly relapse also has a significant financial impact on the healthcare system as a result of the increased use of medical resources and percentage increase in inpatient care. For bipolar disorder, the mean cost of a depressive episode is £2,272 (75% due to inpatient care), while the mean cost of an acute manic episode is £6,437 (90% due to inpatient care) at 2006 prices.⁷ On average, a relapse in schizophrenia costs the NHS £10,950 (over six months at 2006 prices), compared with a cost to the NHS of £2,532 (at 2006 prices) for people with schizophrenia who have not experienced a relapse (75% due to inpatient care).⁸

Minimising the Risk of Relapse

There are many different reasons why relapse occurs, particularly as each person's symptoms will be different. Eliminating the distress of relapse and reducing hospitalisation by following the most effective approach to treatment is a key objective in the management of people with schizophrenia and bipolar disorder.

Think Twice service users' survey results: perceived relapse triggers most commonly reported



Patients were asked the factors they perceive as important in keeping well and the most important factor was the ability to understand their illness, its symptoms and medication:

Think Twice service users' survey results: factors perceived to be important in keeping well

Ranking	Factor	Score (average out of 10)*
1	Understanding my illness, its symptoms and my medication	8.94
2	Support from family	8.14
3	Keeping busy with various activities	7.80
4	Support from friends	7.63
5	Diet and nutrition	7.54
6	Medication	7.39
7	Employment (paid or voluntary)	6.64

Ranking	Factor	Score (average out of 10)
8	Talking therapy (alone with therapist)	6.63
9	More time with doctor	6.63
10	Exercise	6.61
11	Regular check-ups (CPN or equivalent)	6.39
12	Group therapy	3.79

*10 being highest, 1 being lowest

■ Engaging the service user

The *Think Twice* service users' survey revealed some obstacles to service user engagement. One in four UK residents who took part in the survey and had in the past experienced a relapse, felt unable to discuss their worries about relapse with healthcare professionals. The most common reasons for this were perceived unresponsiveness of healthcare professionals, fear (for example of hospitalisation) and insufficient time for discussion due to short and infrequent appointments. Suggesting that the information card published with the accompanying service user booklet be completed together during appointments may be one way to initiate positive discussion about relapse. Creating an atmosphere of openness and trust is particularly important for encouraging help-seeking when the first signs of relapse appear.

■ Stress management

Over half of the people who took part in the *Think Twice* service users' survey felt that stressful life events relating to family, work and living environment, bereavement and financial problems had been a trigger for their relapse. Reducing exposure to stressful events through life-style choices or implementing coping methods to allow service users to deal with stressful situations can help minimise the chance of a relapse.

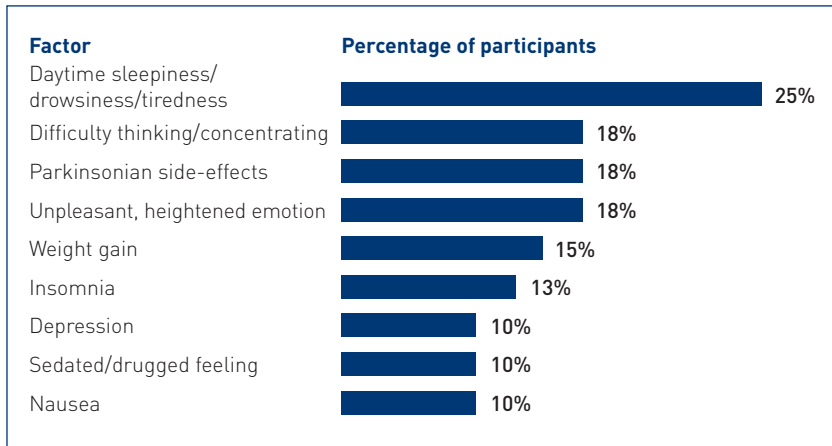
■ Medication

There are many different types of medications available and while the initial priority will be to achieve rapid symptom control, it is important to think about minimising the chance of future relapse from the onset. Over 80% of carers agreed that efficacy is the prime concern when a medicine is chosen. It is important that people fully understand the benefits and risks associated with their medication so they can be involved in decisions regarding their treatment choice.

As you are likely to have encountered, it is not uncommon for people to have difficulty in finding a suitable medication. The *Think Twice* service users' 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 well-being and mental condition.

Poor medication efficacy can be a key cause of relapse – 11% of participants in the *Think Twice* service users' surveyed felt that their most recent relapse was due to their medication no longer being effective. Clinical studies have found differences in discontinuation rates and effectiveness among antipsychotic medications^{9,10} and have demonstrated discontinuing medication increases the risk of relapse by almost five times.⁵

Just over 25% of the service users surveyed felt that stopping their medication had contributed to their last relapse, but worryingly, as many as 65% of survey participants had stopped taking their medication against or without seeking advice from their psychiatrist. There were many different reasons why people stopped taking their medication, but the most common reasons cited were unwanted side effects (57%), feeling better and consequently thinking that medication was no longer needed (40%) and thinking their medication was not working (40%). The survey highlighted a range of side-effects that result in people stopping their medication including:



Considering this, it is important to weigh up the efficacy of medication in controlling symptoms, against concerns people may have regarding tolerability. Patients must be made aware of the risks and benefits of their medication and be provided with strategies to deal with any side-effects that may occur.

■ Physical health

The *Think Twice* service users' survey highlights that physical ill health and excessive alcohol consumption are also significant contributors to relapse. A holistic approach to care, fundamental to ensuring that both mental and

physical health are effectively managed, has recently been advocated in the Department of Health commissioning framework, *Choosing Health – Supporting the Physical Health Needs of People with Serious Mental Illness*.¹¹ Data from the Lilly Well-being Support Programme highlights concerns over the lack of routine measurement and monitoring of the physical health risks of people with severe mental illness with data showing that as many as 69% of participants did not receive any form of physical health check prior to enrolment onto the programme.¹² A number of simple measures can help to significantly improve self esteem, reduce cardiovascular problems and help to maintain a healthy weight. These include awareness of the need to exercise, maintain a healthy diet and stop smoking. Annual physical health checks for people with mental illness have also been included in the ongoing management points of the Quality and Outcomes Framework (QOF) for mental health.¹³

■ Talking therapies

Talking therapies can help service users to recognise problems and develop coping strategies. Cognitive behavioural therapies have been shown to be effective in reducing the severity of psychotic symptoms through helping patients examine the meanings they give to their symptoms and the evidence they hold for their beliefs.¹⁴ It is also known that service users sometimes already use cognitive-behavioural strategies to combat early signs of relapse, and coping strategy enhancement techniques can be used to strengthen those.¹⁵ Cognitive therapy has also been used successfully to reduce recovery time from psychosis.¹⁶

■ 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 that first notice that someone is undergoing a relapse, rather than the person experiencing the relapse themselves. 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 in a similar position and reduce feelings of isolation.

■ Keeping busy

Regularly taking part in activities that service users enjoy and find relaxing, such as a hobby or voluntary work, can help them to develop a productive and fulfilling daily routine which many people find reduces their chance of a relapse. Service users ranked 'keeping busy' third out of twelve factors perceived as being important in keeping well.

About the research

- *Think Twice service users' survey*: 108 individuals with schizophrenia, schizoaffective disorder and bipolar disorder were surveyed about their experience of relapse by SANE either online at www.sane.org.uk or via a telephone interview. The research was conducted during July and August 2006
- *Think Twice psychiatrists' survey*: 103 psychiatrists were surveyed about their views and perception of relapse by independent market research company TNS Healthcare UK. The research interviews were conducted via the web between 31st July and 1st August 2006
- *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 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.

References

1. *Think Twice psychiatrists' survey*: survey of 103 psychiatrists. The research was conducted by an independent market research company (TNS Healthcare UK) via the web between 31st July and 1st August 2006.
2. *Think Twice service users' survey*: survey of 108 people with schizophrenia and bipolar disorder conducted by SANE online at www.sane.org.uk and via telephone interviews during July and August 2006.
3. *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.
4. Lehman AF, Lieberman JA, Dixon LB *et al*. American Psychiatric Association; Steering Committee on Practice Guidelines. Practice guideline for the treatment of patients with schizophrenia, second edition. *Am J Psychiatry* 2004 Feb;161(2 Suppl):1-56.
5. Taylor M, Chaudhry I, Cross M *et al*. Towards consensus in the long-term management of relapse prevention in schizophrenia. *Hum Psychopharmacol Clin Exp* 2005; 20: 175-181. Review.
6. Mangalore R and Knapp M. Cost of Schizophrenia in England report 2006. <http://www.pssru.ac.uk/pdf/dp2376.pdf>
7. McKendrick J, Cerri KH, Lloyd A *et al*. Cost effectiveness of olanzapine in prevention of affective episodes in bipolar disorder in the United Kingdom. Accepted for publication *J Psychopharmacology* Sept 2006.
8. Almond S, Knapp M, Francois C *et al*. Relapse in schizophrenia: costs, clinical outcomes and quality of life. 2004. *British Journal of Psychiatry*. 2004; 184: 346-351.
9. Kinon BJ, Liu-Seifert H and Adams DH. Differential rates of treatment discontinuation in clinical trials as a measure of treatment effectiveness of atypical antipsychotics. Data presented at the International Congress on Schizophrenia Research (ICOSR), 2nd-6th April 2005, Savannah, USA.
10. Tiitonen J, Wahlbeck K, Lonnqvist J *et al*. Effectiveness of antipsychotic treatments in a nationwide cohort of patients in community care after first hospitalisation due to schizophrenia and schizoaffective disorder: observational follow-up study. *British Medical Journal* 2006; doi:10.1136/bmj.38881.382755.2F. [published 6th July 2006]
11. Department of Health. "Choosing Health: Supporting the physical health needs of people with severe mental illness. Commissioning framework." Published 17th August 2006. www.doh.gov.uk.
12. Bushe CJP, Yeomans D *et al*. Physical Health Parameters in Patients with Severe Mental Illness. Baseline data from the Well-being support programme in UK. Data presented at the 25th Collegium Internationale Neuro-Psychopharmacologicum (CINP) Congress, 11th July 2006, Chicago, USA.
13. Department of Health "Quality and Outcomes Framework (QOF)" Published 25th August 2004. www.doh.gov.uk.
14. Kuipers E, Garety P, Fowler D *et al*. London-East Anglia randomised controlled trial of cognitive behavioural treatments for psychosis. I: Effects of the treatment phase. *British Journal of Psychiatry* 1997;171:319-327.
15. Tarrier N, Beckett R, Harwood S *et al*. A trial of two cognitive behavioural methods of treating residual psychotic symptoms in schizophrenic patients: 1. Outcome. *British Journal of Psychiatry* 1993;162: 524-532.
16. Drury V, Birchwood M, Cochrane R *et al*. Cognitive therapy and recovery from acute psychosis: a controlled trial. II. Impact on recovery time. *British Journal of Psychiatry* 1996;169: 602-607.