moving forward
living life with mental health problems:
a guide for black and minority ethnic communities
Who are we?

Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We provide hope and empowerment through effective services and support to all those who need us, and campaign for change through greater awareness and understanding.

To continue our work and build on what we have already achieved, we depend on your membership.

Mental health problems can affect any of us at any point in our lives, no matter what our age or background. In fact, as many as 1 in 4 people in Britain will experience some kind of mental health problem during the course of a year.

If you’re from a black and minority ethnic (BME) group you’re at the highest risk of being diagnosed with severe mental illness. On top of this there’s often a lack of cultural understanding among health professionals which, along with a tendency to stereotype, can lead to inaccurate diagnosis or failure to recognise mental health problems in time.

This can make people from BME groups feel poorly treated and unsupported. Eventually they may stop communicating with mental health services altogether, so their mental health deteriorates. In the worst cases, a crisis situation leads to detention under the Mental Health Act (this is often called “being sectioned”) or involvement with the police.

At Rethink, we’re working hard to make sure this doesn’t happen. Improving the mental health system will take time, but we already have services available in some areas, and will continue to engage with BME groups and help them get the support they need.

In this booklet you’ll find basic information on some forms of severe mental illness and on the issues that may be important for BME communities. We also publish a wide range of information about mental illnesses and related issues.

Throughout this booklet you will see boxes suggesting where you should look “For more information”. These might be useful websites or phone numbers, or could be free booklets or factsheets. Unless it says otherwise, these will be available for free from www.mentalhealthshop.org or by calling 0845 456 0455.

“\1 learnt how to cope through a Rethink group, from other families and from service users.”

For more information: www.rethink.org
What is severe mental illness?
What does mental illness mean? What are the symptoms of mental illness and how is a diagnosis made?
What stops you getting the support you need?
Why do BME groups often have difficulty getting the right support for their mental illness?
Understanding your medication
Medication can be a complicated issue and it’s important that you are aware of what is available and what possible side effects you may experience.

Other treatments
There are many other treatments besides medication that can help with recovery, such as talking treatments and complementary therapies.

Your physical health
If you have mental health problems it’s important to keep a check on your physical health too.

Spirituality
Religion and spirituality can play an important part in people’s lives. Faith can have both positive and negative effects on your mental health.

Self-harm
Deliberately hurting yourself is one of the most distressing symptoms of mental illness. What can you do to keep safe?

Drugs and alcohol
If you have drug and alcohol problems at the same time as a mental health problem, this may cause further complications.

There is help out there
Rethink has developed services to provide support specifically for people from a range of BME communities. These aim to provide appropriate help and information whether you are in contact with other mental health services or not.

How Rethink can help
Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life.

Glossary
What is mental illness?

Different cultures have different approaches to mental and emotional wellbeing. In Britain the accepted approach is known as the medical model. This model views mental health problems in terms of something being wrong (an illness) that needs to be fixed (treated).

To determine what’s wrong, a diagnosis will be made based on the person’s symptoms, how severe they are and how it’s affecting their life. Symptoms can include extreme mood swings, ongoing low mood, hearing voices, or being extremely worried about things to the point of panic. This is not a complete list but just some of the things doctors look for.

But if you’re from a BME group this approach may be inappropriate, because what you’re experiencing could have a very different cultural meaning to you. As a result you may disagree with the diagnosis or treatment plan you’re given.

In an ideal world all health professionals would be educated about different cultural backgrounds and able to provide for people who can’t express their views in English. Sadly this is not always the case. The unfortunate reality is that BME community members are often unable to access the right support and so become more vulnerable to isolation and crisis.

The main types of severe mental illness include:

- Clinical depression
- Anxiety disorders
- Schizophrenia
- Bipolar disorder (manic depression)
- Schizoaffective disorder
- Personality disorders (these are not in the same category as the other illnesses, but can sometimes be associated with mental health problems).

The main symptoms are either related to losing a sense of reality (psychotic) or to moods (affective).

Psychotic symptoms are mainly experienced in schizophrenia, bipolar disorder, schizoaffective disorder, or what is known simply as ‘psychotic disorder’. The usual signs of psychosis are hallucinations (especially hearing voices that seem to be coming from outside your head but are not, and seeing things that are not really there). Delusions are also common - strong, false beliefs that seems strange and irrational to others. They tend to be either paranoid delusions, where you may believe you are being spied upon or persecuted, or grandiose delusions where you’ll believe you are very famous or important.

Mood (affective) symptoms can cause you to experience extreme mood swings, ranging from very low (depression) to very high (mania), often with periods of feeling normal in between. This is bipolar disorder, which used to be called manic depression, and psychosis may be part of the manic phase. Schizoaffective disorder is the name for the experience of both mood swing problems and psychosis. Depression is when your mood is persistently so low that you cannot escape feeling hopeless and sad.

For more information:
- What is Severe Mental Illness? Booklet.
- Rethink Factsheets: Anxiety Disorders, Bipolar Disorder, Depression, Personality Disorders, Schizoaffective Disorder, Schizophrenia
What stops you getting the support you need?

Many things contribute to people from BME groups and their families getting poor support from mental health services.

Different approaches to mental health issues. The medical model used in the UK is based on the idea that something is wrong which needs to be ‘fixed’ with medication. Some BME groups do not identify with this approach.

Seeking help – cultural differences. Different communities will look for help in different ways. Some may not trust mental health services, or may see using them as shameful, so this will mean they are less likely to seek support.

Language problems. Many people living in Britain find it difficult to discuss their experiences in English – a major barrier that can lead to an incorrect diagnosis. In a few cases an interpreter may be available so it is always worth checking. All Rethink services offer support through a translation service called Language Line. People may need to be encouraged to seek available support.

Poor access to non-drug treatments. Very few people from BME groups are offered talking therapies, such as counselling. If you feel you are being denied this option, speak to the National Advice Service about making a complaint.

Lack of BME mental health staff. Although all mental health staff, whatever their background, should try to be more culturally aware, this is not always the case.

Poor risk assessment. Stereotypical views of people from different BME groups can make some mental health staff assume that they are greater risk to the public. As a member of a BME community, you are more likely to be sectioned, medicated by injection or physically restrained by mental health staff or by the police.

For more information: “Inside Outside” Report from the National Institute of Mental Health (NIMH) at www.dh.gov.uk.
Understanding your medication

We strongly believe that you should have access to good, clear information about medications. This will help you understand your options and find out if there’s anything you should be aware of, like the possible side effects.

As part of the UK’s medical approach to mental illness, medication is often the primary form of treatment you will be offered. Different types of medications target different symptoms, and include anti-depressants, anti-psychotics and mood stabilizers. Many people do find that their mood or psychotic symptoms are reduced by medication. Medication is usually in tablet form, but some is available as long-lasting injections.

There’s no guarantee that a particular medication will suit you, and you might need to try several before you find one that’s effective. If you’ve tried a medication for a few weeks and don’t feel that you’re benefiting, it’s important to tell your doctor or psychiatrist. Any changes to medication, including dosage, should be made with the support of whoever prescribed it. Your doctor should also be reviewing your medication regularly, and giving you the chance to discuss how you’re getting on.

For more information:
Only the Best Booklet.
Rethink Factsheets:
Antipsychotics,
Antidepressants,
Mood Stabilisers.
For Advice:
Maudsley Medication Helpline 020 3228 2999

Other treatments

If you have a mental health problem, medication should not be the only option available, but it can be difficult to find out what else is out there. Talking therapies, for example, can be hard to access. Not only are these expensive for the NHS to provide, but there is often a long waiting list for the sessions.

If you’re part of a BME group, you’re less likely to be encouraged to take up this kind of treatment. We hope that by giving you more information about what’s available, you’ll feel more confident to request treatments like these.

Different types of talking therapy include:

Cognitive therapy – helps you change patterns of thinking or behaviour that are causing problems in order to deal better with things.

Family intervention – working on your problems together with your family so they can be actively involved in supporting you.

Supportive counselling – being able to talk about thoughts and feelings without being judged. This can help you decide what you want for yourself and may be useful if you want to make sense of your experiences in a way that you don’t feel conflicts with your cultural background.

There are a number of general wellbeing therapies that can also be useful. These are called “complementary therapies”. They should be used alongside medication rather than instead of it. Sometimes people try these treatments because their medicine is giving them unpleasant side effects. If this does happen it’s always best to talk to your psychiatrist about the problems you’re having with the medicine first.

Complementary therapies that can help with problems like anxiety or sleeping badly include exercise, relaxation or meditation. Other therapies, like art therapy, are designed to help you express your emotional self.

For more information:
Rethink Factsheets:
Talking treatments and psychological therapies,
Complementary therapies
Physical health

Some people with severe mental illness also have very poor physical health. Your symptoms, and the side effects of your medication, can take their toll on your body. But you can combat this by taking care of yourself, and by knowing what to look out for.

More serious physical side effects of medication include weight gain, and perhaps leading to diabetes, problems with and changes to heart function. To avoid these side effects, you should take steps to improve your physical health.

Certain health issues are more important to particular ethnic communities. For example, black Caribbeans are at much higher risk of stroke, with women being most at risk. Black and Asian people are also more likely to develop diabetes and heart disease than the general population. These conditions can be triggered by some medications for mental illness – you should be aware of the risks and carefully monitor your physical health for changes.

It's also very important to cut back on habits like smoking, drinking alcohol and drug use. These could interfere with the effectiveness of your medication, making your symptoms worse and causing major physical problems.

Your doctors have a responsibility too. They should check your physical health regularly, but you might need to remind them to make sure it happens. Most GPs write to people with severe mental illness to offer annual health checks. This will be carried out by a doctor or practice nurse and will involve:

- Taking a blood sample
- Taking a urine sample
- Taking your pulse
- Weighing you
- Listening to your heart
- Asking you about your medication and if you are experiencing any side effects
- Advising you about diet, exercise and smoking.

Finally, regular exercise – even if it's just walking or doing housework – and eating a balanced diet (not too much fat and sugar) will also help your body to fight illness.

A simple rule for a balanced diet is to plan for each meal, which should include:

**Protein:**
- meat, fish, eggs, corn meal, lentils or pulses

**Carbohydrates:**
- rice, potatoes, sweet potatoes, plantain, yam, cassava (boiled rather than fried is much healthier and helps reduce weight if this is a concern)

**Fruit or vegetables:**
- fresh or frozen is best

For more information:
Rethink Factsheet: *Physical Health and Nutrition*
Spirituality

Spirituality and faith are incredibly important to many of us. To put it simply, this is the meaning and purpose that we seek for our lives. It can include religious and non-religious practices like meditation and prayer, belonging to a faith community, or spiritual values like kindness, compassion and hope.

For certain BME communities, spirituality is a way of life. Some research shows that it can help you to stay mentally well. When you’re under a lot of stress, the support of a religious group can help your mental health, even if you don’t have a mental illness. The support you receive following the death of a loved one, for example, is an important factor in avoiding depression.

Despite this, a lot of people feel that their spiritual needs are neglected by treatment and care plans.

Difficulties you may encounter
Faith can be problematic too. If your religious community tells you that your mental illness is the result of religious or moral failings, it could make you feel guilt and shame. Some religious organisations may suggest exorcism as a cure, which might prevent you from seeking professional help, and could be extremely distressing. Deeply religious people may interpret visions, speaking in tongues or hearing voices as signs of faith, rather than symptoms of an illness. But delays in seeking treatment can just make symptoms worse, and put you in danger.

Problems with professionals
Sometimes explaining your experiences in terms of spirituality will also stop you from getting the help you need, because mental health professionals might not understand what you mean.

Beliefs that may be completely normal in your community could seem strange to outsiders, so it’s really helpful if mental health workers can get an understanding of your culture. Unfortunately this doesn’t always happen, and you may feel that your views and needs aren’t being understood. If you’re having difficulty explaining things to a health professional, taking a friend or relative along to your appointment can help.

It’s worth remembering that NHS guidelines require your spiritual needs to be met. So if this isn’t happening you should raise the issue with your psychiatrist or mental health support worker.

“\textbf{I gain strength and support from others like me.}”

For more information:
Rethink Factsheet: \textit{Spirituality and Mental Illness}
Self-harm

Self-harm can involve cutting, burning, scratching or hitting yourself, or even self poisoning using alcohol or drugs. A lot of doctors think that self-harm is like suicide, but we believe people self-harm for very different reasons.

A suicide attempt can be a cry for help or a genuine attempt to kill yourself, but self harm is often done as a way to deal with problems, and can help the person self-harming to feel better. Many self-harmers say that, rather than being an attempt to get attention, it’s the only way they can express the pain they feel inside and get some kind of relief from it.

How can professionals support you?

Mental health professionals may not understand what motivates you to self-harm, so it’s important to explain as best you can why you self-harm and how it helps you cope.

Professionals should be able to help you by providing:

• Support
• Practical help in dealing with situations that could lead to you harming yourself
• Help understanding what motivates you to self-harm
• Psychiatric assessment to identify mental health problems
• Treatment of mental health problems
• Access to talking therapies
• Access to problem solving therapy

As understanding of self-harm improves, we hope that more people will learn to practice safe self-harm, rather than be forced to stop before they are able to cope in other ways.

Tips for staying safe include:

• Don’t share cutting implements with anyone else, as diseases such as HIV/AIDS can be transmitted this way.
• Equip yourself with first aid supplies and knowledge of first aid
• Keep any cutting tools sterile.
• Make sure you know what to do in an emergency (such as dialling 999 for an ambulance)
• Set yourself limits before you self-harm so that you do just enough to relieve your distress and no more.

For More Information:
Rethink Factsheet: Self-harm
Drugs and alcohol

The effects of many street drugs are similar to symptoms of mental illness and it can be difficult to tell one from the other. Sometimes a drug or alcohol problem starts long before mental illness, and using drugs can trigger mental illness.

Sadly, drug and alcohol problems are very common among people with mental illness. Some people use alcohol or drugs to help them deal with their symptoms in the short term, or with the side effects of their medication. But long term, using street drugs and alcohol will only make mental health problems worse. If you have a mental illness and also misuse substances, it’s known as dual diagnosis.

Ideally, mental health teams would liaise closely with drug and alcohol abuse professionals. Unfortunately, mental health staff are rarely trained to deal with drug and alcohol problems. Likewise, drug and alcohol workers often don’t know how to deal with mental illness. If you have a mental illness and you’re also using drugs or alcohol, you should try to find out as much as possible about what help is available.

The most effective treatment is made up of several factors including:

- Medication to treat mental illness
- Education about the illness and effects of substances
- Family involvement
- Cognitive behavioural therapy to help you deal with things in a positive way.

For more information:
Adfam and Rethink leaflet: *Dual Diagnosis*
Rethink Factsheet: *Dual Diagnosis*

There is help out there

We understand why you might feel worried about approaching mental health services if you feel that the professionals may not understand you. We provide a number of services for BME groups, designed to give you the practical advice and information that is appropriate to your cultural needs:

The Bristol BME Service
St. Paul’s Settlement,
74-80 City Road, Bristol, BS2 8UH
Tel: 0117 903 1803

Provides support that is accessible and appropriate to the needs of people from BME groups experiencing mental or emotional distress.

The Gravesend BME Service
4-5 High Street, Gravesend,
Kent, DA11 0BQ
Tel: 01474 364498

A befriending and information service called Sahayak is based here. This service also runs a carer support group each month.
We operate a National Advice Service which provides expert advice and information to people with mental health problems and those who care for them, as well as giving help to health professionals, employers and staff. To contact the National Advice Service, please call the Rethink Welcome Team on 0845 456 0455. The National Advice Service is open from Monday to Friday 10am – 3pm, except Tuesdays and Thursdays when it is available 10am to 1pm.

There are also other national organisations which provide BME specific information and support.

**The Afiya Trust**
27/29 Vauxhall Grove, London, UK
Tel: 0207 582 0812
Web: www.afiyatrust.org.uk

**BME Mental Health Network**
(at the Afiya Trust)
27/29 Vauxhall Grove, London, UK
Tel: 0207 582 0812
Web: www.bmementalhealth.org.uk

To find out how Rethink can help you or where your nearest Rethink support group or service is call **0845 456 0455**, 9am to 5pm Monday to Friday, or visit [www.rethink.org](http://www.rethink.org). You can also email us at info@rethink.org

We operate a National Advice Service which provides expert advice and information to people with mental health problems and those who care for them, as well as giving help to health professionals, employers and staff. To contact the National Advice Service, please call the Rethink Welcome Team on 0845 456 0455. The National Advice Service is open from Monday to Friday 10am – 3pm, except Tuesdays and Thursdays when it is available 10am to 1pm.

We also produce a wide range of information on severe mental illness, most of which is free. We have more than 30 years’ experience of helping people affected by severe mental illness and their families towards recovery. We provide over 350 mental health services including employment and training services, housing, advocacy, and community support. We also run over more than 130 support groups across the country.

**The Asian Mental Health Helpline**
Tel: 0808 800 2073
A culturally sensitive listening and information service for the Asian community in Kent, East Sussex, Brighton and Bexley.

**Ealing Carers Support Service**
15, Central Chambers, The Broadway, Ealing, London, W5 2NR
Tel: 0208 567 0101
This service provides carers with support, advice, information and advocacy.

**For more information:**
0845 456 0455
[www.rethink.org](http://www.rethink.org)

“My recovery, like many others, has been likened to climbing a flight of stairs, which we all have to do, one step at a time.”
Joining Rethink is easy
If you’re affected by mental Health Problems and would like help, information or advice, or if you share our vision of fairer, more enlightened mental health care fit for the 21st century, we want you to join us.

Our ‘Pay What You Can’ membership scheme means you don’t have to pay to join, but please make a donation if you can to cover the costs. Apply online at www.rethink.org or call 0845 456 0455. Please join us today.

Information on mental health
For more information about Rethink, please visit www.rethink.org. To view or order publications relating to mental health, please visit www.mentalhealthshop.org or call 0845 456 0455.

Got any comments about our services?
Have we done well, got it wrong or not quite right? Please contact quality@rethink.org or call 01823 365 300

Diversity and equality
Working together to value difference and release talent.

This brochure has been printed with an educational grant from Janssen-Cilag Ltd. As part of their ongoing commitment to the field of mental health, Janssen-Cilag Ltd runs a health awareness campaign, called 1 in 100, which aims to provide people living with schizophrenia and their families and friends with information. The views expressed are those of Rethink and not of Janssen-Cilag

For further information please visit:
www.oneinonehundred.co.uk
www.janssen-cilag.co.uk

Glossary

Antipsychotics
These drugs reduce psychotic symptoms such as hallucinations and delusions.

Bipolar disorder (manic depression)
People with this illness experience cycles of very low mood (depression) and very high mood (mania), often with periods of feeling normal in between.

BME
Black and minority ethnic groups. These include non-UK white groups such as Eastern European and Irish.

Clinical Depression
The symptoms of this condition may include a loss of interest in pleasurable activities, and strong feelings of sadness and hopelessness.

Delusions
Delusions are firmly held false beliefs that seem strange and irrational to others. They can be delusions of paranoia or perhaps grandeur. These beliefs might incorporate other symptoms like hallucinations.

Dual Diagnosis
This is the term used when a person has a mental illness and also misuses substances such as street drugs or alcohol.

Hallucinations
This is when a person perceives things that do not really exist. They may hear voices or see things that are not there. These are the most common types of hallucination, but they can affect any of the senses.

Personality Disorder
This is the name used to describe people whose personality traits cause them long term problems with relating appropriately to others and to life in general.

Psychosis
This is when a person loses their sense of reality and experiences the outside world in a distorted way. Psychotic symptoms include hallucinations and delusions.

Schizoaffective disorder
This is when the symptoms of mood disorder (depression and mania) and symptoms of schizophrenia occur at the same time.

Schizophrenia
The most commonly diagnosed severe mental illness. Psychotic symptoms and a withdrawal from reality and from normal life are common symptoms.
Working together to help everyone affected by severe mental illness recover a better quality of life

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