# Talking about mental health

A resource that explores how mental health conditions are described, and helps you define your experiences in your own terms



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## Introduction

#### **Using this book**

This book from Together's Directorate of Service-user Involvement looks at the different ways in which different types of mental distress can be described. It shows that many mental health conditions are described in very different ways by different groups of people – such as doctors, people in other parts of the world, and, most importantly, those who experience them.

This in turn helps us remember that the medical way of describing mental health problems is just one among many different ways of looking at mental distress. It shows too that clinical diagnoses often seem more negative, pessimistic and judgemental than other ways of perceiving these experiences.

We have written this book because at Together we want to demystify mental health jargon, and focus on people's emotional experiences, personal journeys and potential, rather than pessimistic clinical diagnoses.

Each page contains several different definitions of one common mental health condition:

- a dictionary definition from the New Oxford Dictionary of English
- a condensed medical definition from the Diagnostic and Statistical Manual of Mental Disorders IV-TR, which is the tool psychiatrists use to help them make diagnoses
- definitions from around the world examples of similar 'illnesses' and symptoms found in other cultures
- **Together definitions** some examples of ways in which people at Together have told us they might prefer to describe the condition, using plain English.

At the end of each section there is space for you to write down in your own words how *you* feel. You may find it helpful to use **your definition** of what you experience to help you explain to other people (including professionals) what your experience of mental distress is like.

We have also included a couple of pages in the middle of the book for you to use to talk about your mental health, and the language you do – and don't – like to use to describe it. You can photocopy the pages as many times as you like, so you don't need to worry about running out of space. If, like many people, your feelings change from day to day you could create a diary of your experiences. Feel free to use the pages inventively to create a scrapbook of drawings, cuttings and images.

#### **Medical definitions**

Medical labels and diagnoses can be confusing. They also pigeonhole people in a frightening way. So when you read the medical definitions in this book do bear in mind that they should be treated with caution.

You may find some of the wording used in them offensive, and the descriptions given may not reflect the way you see yourself and your condition. These definitions are not meant to scare or limit you – they are simply here to inform you about official medical thinking.

#### Definitions from around the world

Other cultures have very different – and frequently much more poetic or evocative – ways of talking about mental distress, and symptoms can take on different connotations according to where in the world you are. For example, in one country hearing ancestral voices may be celebrated instead of being seen as a symptom of an upsetting experience that is called schizophrenia by medics. There are some illnesses that seem only to exist in one country or culture (which again calls into doubt the validity of the 'objective' medical way of categorising illnesses). We have included some of these descriptions even though they do not reflect exactly Western medical diagnoses. Most of the definitions from around the world that we have listed are found on the following website: http://weber.ucsd.edu/~thall/cbs\_intro.html

We cannot guarantee the accuracy of these definitions or their translations. If you are interested in reading more about global views of mental distress however, the site provides a starting point for further research into 'culture bound syndromes'.

#### **Together definitions**

We have also included some plain English expressions such as 'I have dark thoughts' and 'I get in a sweat about things', which people we know have used to describe how they feel.

Your feelings are unique, and at Together we believe that you are the expert on your own experience. And we hope this book will help give you confidence when talking about how you feel with the mental health and medical professionals with whom you come into contact. We would like to hear how you describe yourself if you want to share your feelings. You can send your own definitions to us by using the contact details on the back cover.

The Western psychiatric tradition offers only one way of categorising individual experience. We hope that this resource helps you to look beyond the labels we get given, to celebrate diversity and take pride in your own individuality.

# Anxiety

noun [mass noun] ORIGIN early 16<sup>th</sup> cent.: from French *anxiété* or Latin *anxietas*, from *anxius* (from *angere* 'to choke')

#### **Dictionary definition**

A feeling of worry, nervousness, or unease, typically about an imminent event or something with an uncertain outcome.

- [with infinitive] desire to do something, accompanied by apprehension.
- Psychiatry a nervous disorder marked by excessive uneasiness and apprehension, typically with compulsive behaviour or panic attacks.

New Oxford Dictionary of English

We have included the DSM definitions to inform you about official medical thinking.

They can be confusing and sound judgemental, and you may find them offensive.

We suggest that you use them as a starting point to challenge accepted views and write your own definitions.

#### **DSM** definition

Diagnostic Criteria for Generalised Anxiety Disorder:

Excessive anxiety and worry (apprehensive expectation), occurring more days than not for at least six months, about a number of events or activities (such as work or school performance). The person finds it difficult to control the worry.

The anxiety and worry are associated with three (or more) of the following six symptoms (with at least some symptoms present for more days than not for the past six months). Note: only one item is required in children.

- restlessness or feeling keyed up or on edge
- being easily fatigued
- difficulty concentrating or mind going blank
- irritability
- muscle tension
- sleep disturbance.

Diagnostic and Statistical Manual of Mental Disorders

'Narahatiye qalb' – Pounding heart and feelings of panic.

Iran and Middle East

'Shenkui' – Dizziness, frequent dreams and worry.

China

'Shin-byung' – Fear, loss of appetite, insomnia.

Korea

'Ataque de nervios' – Attacks of crying, shouting and feelings of heat rising in the head or chest.

Latin America

- I can't let go of thoughts which are usually negative.
- I go on and on about details which seem to be negative.
- I get in a sweat about issues and tasks that most people don't give a second thought to.
- I feel 'wired' and tense and have an urge to escape from situations that fill me with dread.
- In a panic attack I become short of breath, my heart races and I feel dizzy and disorientated.

My definition		

# Bipolar disorder

Bipolar ◆ adjective: Having or relating to two poles or extremities. Disorder ◆ noun [mass noun] ORIGIN late 15<sup>th</sup> cent. (as a verb in the sense 'upset the order of'): alteration, influenced by ORDER, of the earlier *disordain*, from Old French *desordener*, ultimately based on Latin ordinare 'to ordain'

#### **Dictionary definition**

(of psychiatric illness) characterised by both manic and depressive episodes, or manic ones only.

New Oxford Dictionary of English

#### **DSM** definition

Diagnostic Features:

The essential feature of **Bipolar I** disorder is a clinical course that is characterised by the occurrence of one or more Manic Episodes or Mixed Episodes. Often individuals have also had one or more Major Depressive Episodes...The essential feature of **Bipolar II disorder** is a clinical course that is characterised by the occurrence of one or more Major Depressive Episodes accompanied by at least one Hypomanic Episode...The symptoms must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

The following specifiers may be used:
Mild, Moderate, Severe without
Psychotic Features; Severe with
Psychotic Features; Chronic; With
Catatonic, Melancholic, Atypical
Features; With Postpartum Onset;
Longitudinal Course Specifiers (With and
Without Interepisode Recovery);
With Seasonal Pattern; With Rapid
Cycling.

Diagnostic and Statistical Manual of Mental Disorders

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'Boufée deliriante' – Agitation, confusion and excitement.

West Africa and Haiti

'Arctic hysteria' – Episode of excitement often later forgotten. Those affected may shed their clothes, break things, shout, run outside or put their safety at risk.

Greenland Eskimos

'Zar' – Laughing, shouting, singing, weeping and withdrawal: thought to be linked with spirit possession.

North Africa and Middle East

- I feel elated and then experience very low moods, where the swing between both moods is rapid.
- I can be bouncy and gloomy almost simultaneously.
- When I am 'high' I have boundless energy, experience a flood of creative ideas and have no social inhibitions.

My definition			

# Dementia

#### noun [mass noun] ORIGIN late 18th cent.: from Latin demens, dement

#### **Dictionary definition**

Medicine A chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning.

New Oxford Dictionary of English

#### **DSM** definition

Diagnostic Features:

The essential feature of a dementia is the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning. The cognitive deficits must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning.

A diagnosis of a dementia should not be made if the cognitive deficits occur exclusively during the course of a delirium. However, a dementia and a delirium may both be diagnosed if the dementia is present at times when the delirium is not present. Dementia may be etiologically related to a general medical condition, to the persisting effects of substance use (including toxin exposure), or to a combination of these factors.

Memory impairment is required to make the diagnosis of a dementia and is a prominent early symptom. Individuals with dementia become impaired in their ability to learn new material, or they forget previously learned material. Most individuals with dementia have both forms of memory impairment, although it is sometimes difficult to demonstrate the loss of previously learned material early in the course of the disorder. They may lose valuables like wallets and keys, forget food cooking on the stove, and become lost in unfamiliar neighbourhoods. In advanced stages of dementia, memory impairment is so severe that the person forgets his or her occupation, schooling, birthday, family members, and sometimes even name.

Diagnostic and Statistical Manual of Mental Disorders

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'Becoming a child again' – Helpless behaviour in an elderly person who is believed to have overstayed their time on earth and been reincarnated.

#### Senegal

'Hsieh-ping' – Disorientation and delirium: being in a trance state.

Taiwan

My definition

- I have a memory loss, particularly about recent events.
- I recall and dwell on people and events from the distant past.
- I am confused, irritable, anxious and depressed.
- My moods fluctuate and my personality changes significantly.

my domination		

# In my own words

Here are some ideas to help you to explore what your experience of mental distress feels like. Get in touch with your stories and descriptions – your words can help us set new standards for describing mental health issues.

How I feel about the medical language professionals use about me	

What my family and friends say about my experience

Ways of describing mental distress that I find acceptable

Ways of describing mental distress that I don't find acceptable

# Depression

# noun [mass noun] ORIGIN late Middle English from Latin depressio(n-) from deprimere 'press down'

#### **Dictionary definition**

Severe despondency and dejection, typically felt over a period of time and accompanied by feelings of hopelessness and inadequacy.

Medicine a condition of mental disturbance characterised by such feelings to a greater degree than seems warranted by the external circumstances, typically with lack of energy and difficulty in maintaining concentration or interest in life: clinical depression.

New Oxford Dictionary of English

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#### **DSM** definition

Criteria for Major Depressive Episode:

Five (or more) of the following symptoms have been present during the same two-week period and represent a change from previous functioning; at least one of the symptoms is either depressed mood or loss of interest or pleasure.

- depressed mood most of the day, nearly every day
- markedly diminished interest or pleasure in all, or almost all activities most of the day, nearly every day
- significant weight loss when not dieting or weight gain, or changed appetite
- insomnia or hypersomnia
- psychomotor agitation or retardation
- fatigue or energy loss
- feelings of worthlessness or excessive or inappropriate guilt
- diminished ability to think or concentrate, or indecisiveness
- recurrent thoughts of death, suicidal ideation or a suicide attempt.

Diagnostic and Statistical Manual of Mental Disorders

'Brain fog' – Fatigue from too much thinking, difficulty concentrating, pressure and burning around the head.

#### West Africa

'Shenjian shuairuo' – Physical and mental fatigue, sleep disturbance, difficulty concentrating, headaches and other pains.

#### China

'Dhat' – Feelings of weakness or exhaustion.

India

My definition

- I feel a constant low mood that disables me.
- I can't see even a glimmer of light at the end of the tunnel.
- I have dark, frightening and uncomfortable thoughts that plague me.
- I am so depressed it physically hurts.

my definition			

# Hyperactivity

Hyper- ◆ [prefix] from Greek *huper* over; beyond. Activity ◆ noun [mass noun] ORIGIN late Middle English: from French *activité* or Latin *activitas*, from Latin *act-* 'done', from the verb *agere* 'to do'

#### **Dictionary definition**

Hyperactive [adjective]: abnormally or extremely active.

New Oxford Dictionary of English

#### **DSM** definition

Diagnostic Criteria:

The essential feature of Attention-Deficit/Hyperactivity Disorder is a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequently displayed and more severe than is typically observed in individuals at a comparable level of development...

Some impairment from the symptoms must be present in at least two settings (e.g. at home and at school or work). There must be clear evidence of interference with developmentally appropriate social, academic, or occupational functioning...

Inattention may be manifest in academic, occupational or social situations. Individuals with this disorder may fail to give close attention to details or may make careless mistakes in schoolwork or other tasks...

Individuals often have difficulty sustaining attention in tasks or play activities and often find it hard to persist with tasks until completion. They often appear as if their mind is elsewhere or as if they are not listening...

There may be frequent shifts from one uncompleted activity to another...

Hyperactivity may be manifested by fidgetiness... by appearing to be often 'on the go' or as if 'driven by a motor', or by talking excessively... In adolescents and adults, symptoms take the form of feelings of restlessness and difficulty engaging in quiet sedentary activities.

Diagnostic and Statistical Manual of Mental Disorders

'Perdida del Alma' – Restlessness and excitability.

Latin America

#### At Together we might say

- I have boundless energy, feel alert and need little sleep.
- I switch my attention from one subject to another all the time.

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# My definition

# Phobia

# noun ORIGIN late 18th cent.: independent usage of -phobia via Latin from Greek

#### **Dictionary definition**

An extreme or irrational fear of or aversion to something.

New Oxford Dictionary of English

#### **DSM** definition

Diagnostic Criteria for Specific Phobia:

Marked and persistent fear that is excessive or unreasonable, cued by the presence of or anticipation of a specific object or situation (e.g. flying, heights, animals, receiving an injection, seeing blood).

Exposure to the phobic stimulus almost invariably provokes an immediate anxiety response, which may take the form of a situationally bound or situationally predisposed Panic Attack.

The person recognises that the fear is excessive or unreasonable.

The phobic situation(s) is avoided or else endured with intense anxiety or distress.

The avoidance, anxious anticipation, or distress in the feared situation(s) interferes significantly with the person's normal routine, occupational (or academic) functioning, or social activities or relationships, or there is marked distress about having the phobia.

In individuals under 18 years, the duration is at least six months.

Diagnostic and Statistical Manual of Mental Disorders

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'Shinkeishitsu' – Perfectionism, worry about social situations and fear of illness.

Japan

'Taijin kyofusho' – Fear that other people dislike one's body or appearance.

Japan

'Pa-feng and pa-leng' – Fear of exposure to too much yin energy through being in wind or cold respectively.

China

- I can't survive without repeating actions: for example hand cleaning, turning off electrical appliances.
- I am convinced for much of the time that others will abandon me, get ill etc.
- I feel terror and panic that I realise are unrealistic in proportion to the thing I worry about, but can't overcome my fears.
- I feel sick, clammy and breathless and my heart pounds when confronted with my phobia (having a panic attack).

My definition		

# Schizophrenia

# noun [mass noun] ORIGIN early 20<sup>th</sup> cent.: modern Latin, from Greek skhizein 'to split' + phrēn 'mind'

#### **Dictionary definition**

A long-term mental disorder of a type involving a breakdown in the relation between thought, emotion, and behaviour, leading to faulty perception, inappropriate actions and feelings, withdrawal from reality and personal relationships into fantasy and delusion, and a sense of mental fragmentation.

New Oxford Dictionary of English

#### **DSM** definition

Diagnostic Criteria

Characteristic symptoms:

Two (or more) of the following, each present for a significant portion of time during a onemonth period (or less if successfully treated):

- delusions
- hallucinations
- disorganised speech (e.g. frequent derailment or incoherence)
- grossly disorganised or catatonic behaviour
- negative symptoms, i.e. affective flattening, alogia, or avolition.

Note: only one symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other.

For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected levels of interpersonal, academic, or occupational achievement).

Classifications of longitudinal course that may be applied:

Episodic with Interepisode Residual Symptoms; With Prominent Negative Symptoms; Episodic With No Interepisode Residual Symptoms; Continuous; With Prominent Negative Symptoms; Single Episode in Partial or Full Remission; Other or Unspecified Pattern.

Diagnostic and Statistical Manual of Mental Disorders

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'Spell' – Folk term for a trance in which people 'talk to' dead relatives or spirits.

Southern US states

'Locura' – Behaviour that does not follow social rules, agitation, hallucinations.

Latin America

'Ghost sickness' – Obsession with death, hallucinations, disturbed dreams and feelings of suffocation and futility.

American Indian groups

- I hear voices and/or have visions.
- I hold strong beliefs that others do not understand. I have thoughts that are persistent, and this interrupts my life.

	My definition
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# Self-harm

Self ◆ noun ORIGIN Old English, of Germanic origin: related to Dutch zelf and German selbe. Harm ◆ noun [mass noun] ORIGIN Old English hearm (noun), hearmian (verb), of Germanic origin: related to German Harm and Old Norse harmr 'grief, sorrow'

#### **Dictionary definition**

Harm: Physical injury, especially that which is deliberately inflicted.

New Oxford Dictionary of English

#### **DSM** definition

There is no DSM category for self-harm. Self-mutilation is mentioned in the Diagnostic Criteria for Borderline Personality Disorder, where one of the indicators for the condition is given as: 'recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour' (if part of a pervasive pattern of instability and present in a variety of contexts). Five or more indicators need to be present for a diagnosis of Borderline Personality Disorder to be made.

Diagnostic and Statistical Manual of Mental Disorders

The website of the National Self-Harm Network at www.nshn.co.uk dispels some common myths and gives the following facts about self-harm.

Self-injury and suicide have an intimate relationship, but are different.

- Self-injury often represents the prevention of a suicidal period.
- Self-injury is one way of averting suicide.
- Self-injury may be a survival strategy.
- Self-injury is frequently the least possible amount of damage and represents extreme self-restraint.

A diminishing sense of worth may culminate in suicide as its ultimate expression.

People who self-injure are statistically at a greater risk of going on to commit suicide.

Accident and emergency staff may assume that the severity of the injury represents the severity of the condition. This leads to some common misconceptions:

'If it's not an artery they don't mean it. It's acting out.'

'Minor injuries are attention-seeking and aren't serious.'

'Serious injuries mean psychosis.'

'It's masochism.'

People who self-injure have responded that self-harm is not an easy way of attracting attention, a behaviour or development 'disorder' or a diagnosis – it is a private activity and accident and emergency departments will see only a few of the injuries before healing. Commonly it is a dialogue with yourself: an expression of inexpressible emotion or an absence of self-value. The seriousness of an injury may not indicate the extreme distress that the injury represents.

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'Koro' – Fear that the genitals will retract into the body and cause death: people may self-injure to prevent this.

South-east Asia

- I injure myself by cutting or hitting my body as a way of dealing with deep feelings of distress.
- I misuse alcohol or drugs.
- My relationship with food is uncomfortable, even destructive.
- I get involved in abusive relationships.
- I punish or distract myself to cope with numb feelings or painful memories.
- Expressing myself through a 'silent scream' is the only way I have of communicating or taking control.
- I hide the evidence from friends and family.

My definition

This booklet from Together's Directorate of Service-user Involvement looks at how common mental health issues are described by different groups including doctors, dictionary writers, and the people who live with them around the world. For each experience the book gives:

- a dictionary definition
- a medical definition
- examples of what people around the world say
- examples of what people at Together have said.

Most important of all there is also space for you to write down your own thoughts and feelings about your experiences because at Together we believe that you are the expert, and your own experience is just as meaningful as an official diagnosis.

This book is designed to support you to talk to people like professionals using language you feel comfortable with rather than medical jargon. We hope you will use it to challenge stereotypes, record your goals and celebrate your individuality.

For more information contact:
Together's Directorate of Service-user Involvement
82a Wick Street
Littlehampton
West Sussex BN17 7JS
01903 733443
Email serviceuser-involvement@together-uk.org
www.together-uk.org