BREAKING DEPRESSION

The SANE guide to **Major Depressive Disorder (MDD)**

Information and advice to help you navigate your way through major depressive disorder

SANE is a charity which provides emotional support, guidance and information to anyone affected by mental illness, including families, friends and carers. We believe that no one affected by mental illness should face crisis, distress or despair completely alone.

Marjorie Wallace, founder and CEO of SANE, says:

"This guide is for anyone affected by major depressive disorder, one of the most severe and distressing conditions, and one where help is available, but we know it can be hard to find. We hope you find the information about symptoms, diagnosis, assessment and treatment options useful and practical."

This material has been co-created by Janssen-Cilag Limited and SANE mental health charity, and funded by Janssen.

This guide is intended for people diagnosed with depression, those who think they may have depression, and carers of those with depression.

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SANE
www.sane.org.uk

Janssen Neuroscience
PHARMACEUTICAL COMPANIES OF Johnson&Johnson

01 What is depression?

In the Japanese art of Kintsugi, the mending of broken ceramics with gold lacquer celebrates an object's cracks and imperfections; analogous to the recovery from depression, by taking each broken piece one at a time, we can recognise the beauty and uniqueness of every journey

The term 'depression' covers a range of symptoms and disorders that occur on a spectrum. Everyone occasionally experiences depressive symptoms in daily life – they are a part of normal human experience. For some people, these symptoms cross the boundary to a mental health problem or illness because they significantly impact their day-to-day life.[1] We need to be clear on what we're talking about, so first we'll explain the different types of depression.[2]

Depression: The period from when the depression begins, up until it is successfully treated, is called a 'depressive episode'. A healthcare professional may tell you you're going through a 'mild', 'moderate' or 'severe' episode. If it has lasted for 2 years or longer, it is known as 'persistent'.[2] If you've experienced two or more episodes in your lifetime, it is 'recurrent'.[2] If it has been caused by a stressful life event, it is 'reactive'.[2]

Major depressive disorder (MDD): MDD is diagnosed when at least five symptoms of depression (which must include depressed mood and/or loss of interest or pleasure in activities) which cause clinically significant distress or impaired functioning almost every day for at least a 2-week period.[3]

Treatment-resistant depression (TRD): If you have tried two or more unsuccessful antidepressant treatments, depression is classified as treatment-resistant.[4]

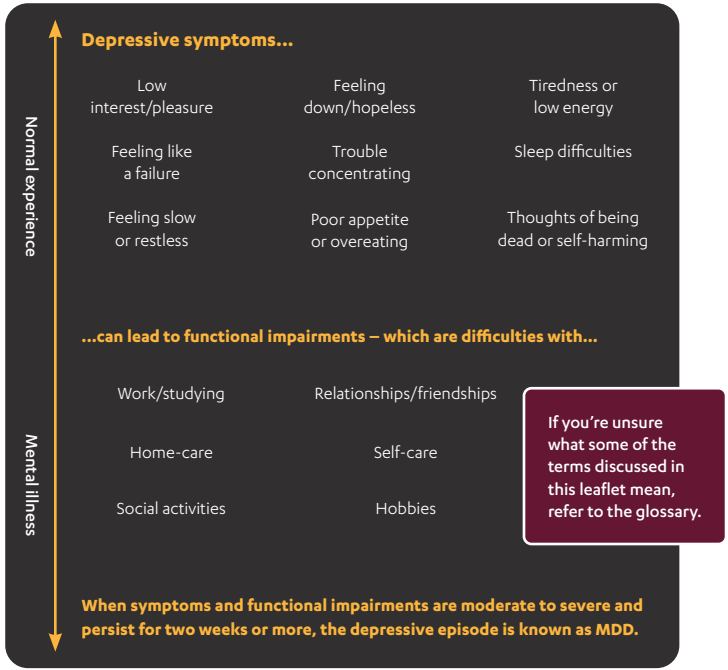
Psychotic depression: Severe depression can sometimes involve hallucinations (hearing, seeing, smelling, tasting or feeling things that aren't real), delusions (beliefs that don't match reality) or racing thoughts. These are also symptoms of psychosis.[2]

Seasonal affective disorder (SAD): Depression can follow a seasonal pattern, such as when the weather gets colder or warmer – occurring most commonly during winter.[2]

Pre-natal or post-natal depression: Depression can occur during pregnancy or following birth, in men and women.[2]

Bipolar disorder: Called 'manic depression' in the past, bipolar disorder is a different illness from depression but often involves cycles of depression and extreme highs (mania).[2]

While this leaflet may contain useful information across the spectrum of depressive symptoms and disorders, the focus will be on MDD.



02 Why could I have depression?

A range of possible factors could be the cause of depression

Depression may be, but is not always, related to a stressful life event such as:[5]

- Loss of employment
- Financial insecurity
- Long-term or life-threatening physical health problems
- Exposure to violence
- Separation
- Bereavement.

Depression may also be related to childhood trauma, such as:[5]

- Exposure to domestic violence
- Abuse
- Neglect
- Separation from parents.

Depression could be caused by one of these factors, or a combination.[5]

Sometimes these kinds of events will cause reactive depression, which later develops into MDD due to the symptoms not being well-managed and worsening.[5]

Various biological factors may cause depression too, such as genetics, too little of a brain chemical called serotonin (which some antidepressants work to increase), or physical health conditions such as diabetes or arthritis.[5-7]

MDD also puts us at higher risk for other physical and mental health conditions.[6,7]

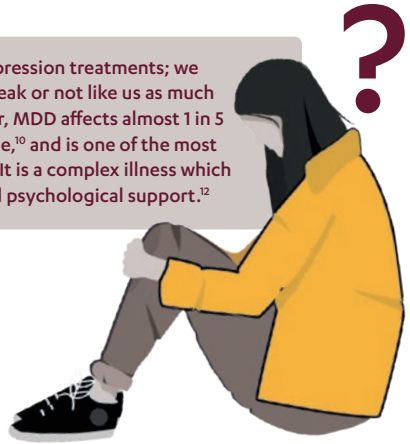
Should I seek a diagnosis?

The decision to seek a diagnosis for depression is entirely your own.

The main reason for seeking a diagnosis is so you can access treatment. It is true that there is no 'silver bullet' - sometimes patients have to try a few medications or try a few therapists or types of therapy until it all 'fits'. But it is possible to recover from MDD.

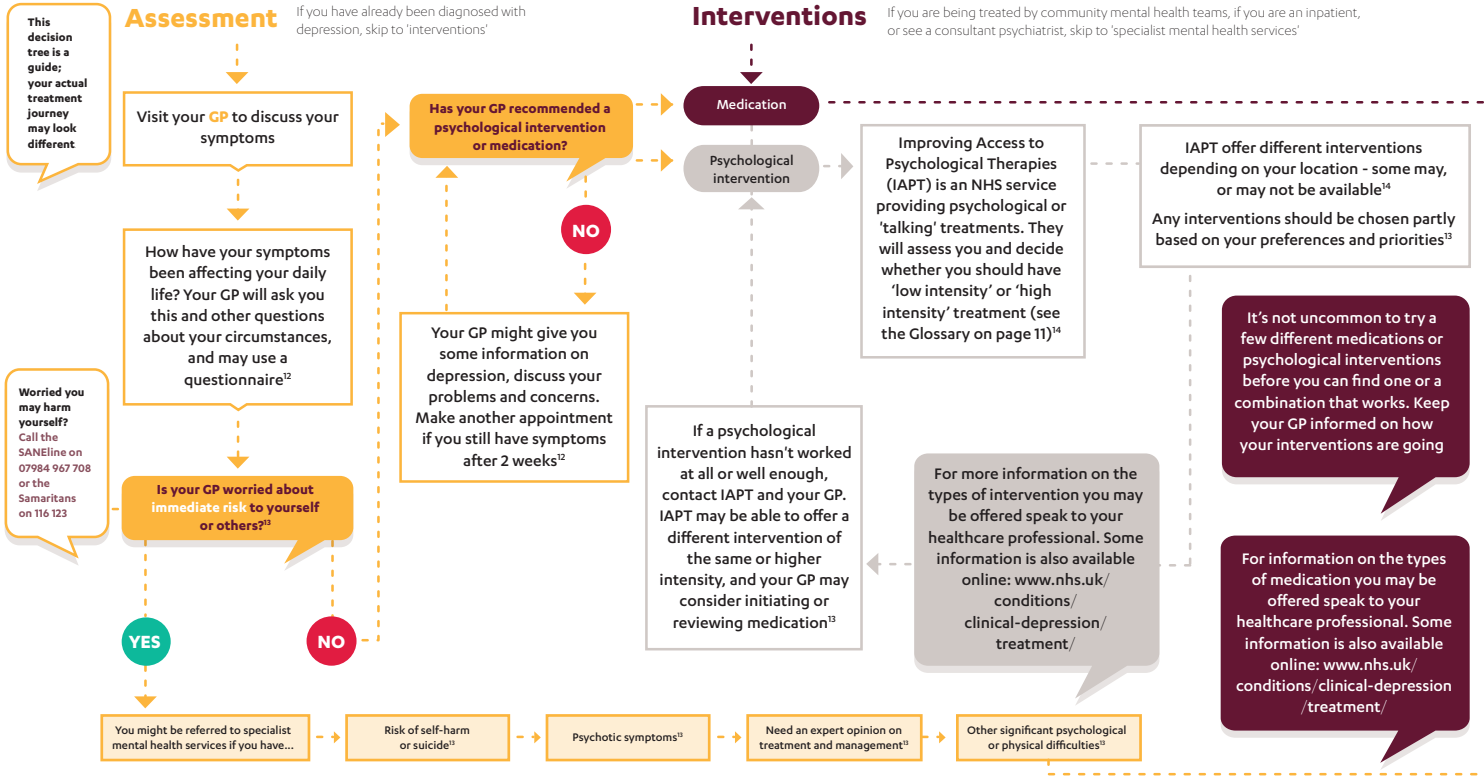
Research suggests one of the reasons people who feel depressed hide their symptoms and don't seek help is stigma.[8] Stigma involves feeling that others have a negative attitude towards you because of your condition, which is then internalised as self-stigma, so you feel and think the same way.[9]

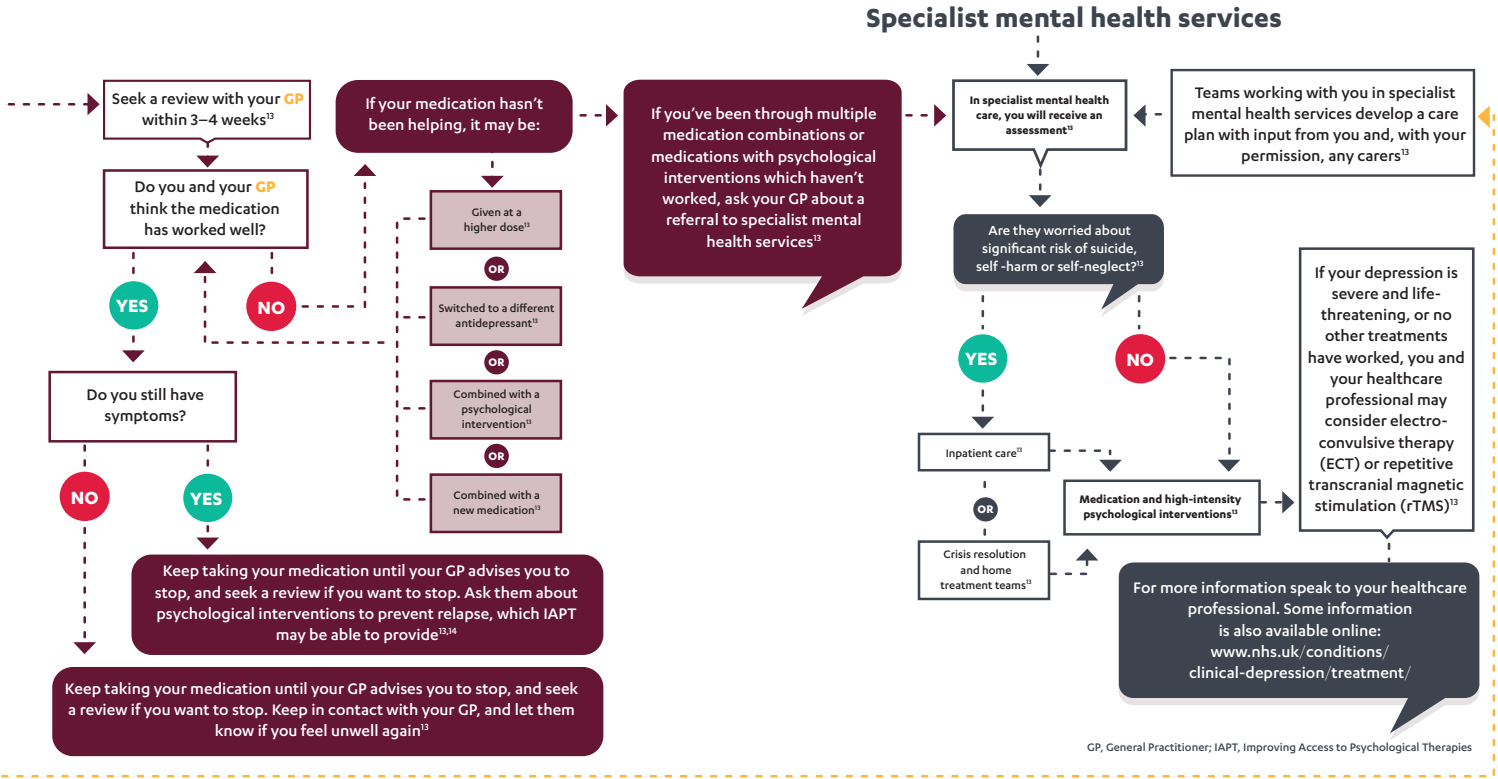
Stigma also affects views of depression treatments; we may feel others will see us as weak or not like us as much if we need treatment.[9] However, MDD affects almost 1 in 5 people in the UK in their lifetime,[10] and is one of the most disabling illnesses worldwide.[11] It is a complex illness which benefits from both medical and psychological support.[12]



03 Your care pathway through depression

Seeking help is the first step on the road to recovery





GP, General Practitioner; IAPT, Improving Access to Psychological Therapies

04 Navigating MDD treatment

We can guide you through your options of care

Assessment

GPs are the first point of contact when discussing depression. You should tell them how you have been feeling and for how long. They may also go through a questionnaire with you.[13]

Some patients feel questionnaires don't reflect the complexity of their experiences or are impersonal; but there isn't a physical test for depression like a blood test. Similar to how diagnosing a physical health problem often involves several steps, assessments for depression consider how your symptoms affect your daily life, your health and treatment history, relationships and living conditions.[13]

Questionnaires can also help to monitor risk. Research shows patients with MDD are 20 times more likely to take their own life than the general population,[15] so healthcare professionals need to know if you are at risk of harming yourself or taking your own life, and how high the risk is, so they can give you the care you need.[13]

If you need support or are thinking about taking your own life, call these helplines:

SANEline 0300 304 7000
Visit **sane.org.uk** for more details.

Samaritans 116 123
(Open 24 hours)
jo@samaritans.org

Interventions – Psychological

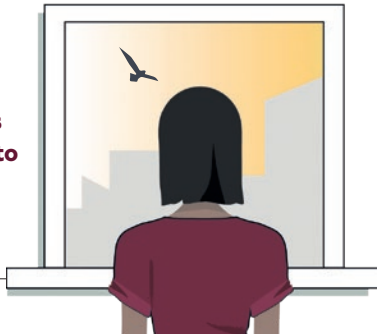
After your assessment, it is for your GP to decide how severe your symptoms are and discuss treatment options with you.

Psychological interventions are usually delivered through Improving Access to Psychological Therapies (IAPT) services, who offer 'talking therapies' such as Cognitive Behavioural Therapy (CBT) and Interpersonal Therapy (IPT) (for more information on these therapies see the Glossary on page 11).

Page 11 has resources which may help if you are on a waiting list, which can take up to a few months in some locations.[14]

The quality of your relationship with your therapist can influence how well therapy works – a good relationship should be based on trust so that you can talk openly.[16] There may be conflict or disagreement, but research suggests working through difficulties in a therapeutic relationship can make it stronger.[17] If you don't think the relationship is working for you, try to tell your therapist why. You could consider requesting a different therapist, if you are able to do so.

You can access IAPT through your GP or you can self-refer, over the phone or sometimes online; see page 10 for a link to find your local service.



Interventions – Medication

Antidepressants (ADs) are another treatment option if you have MDD.

There can be myths or misinformation about ADs, so we'd like to dispel these with some facts:

- ADs are more effective than no treatment; a large study comparing ADs found that of 21 different types investigated, all were significantly more effective than a placebo.[18]
- Some say ADs take weeks to months to work, but new research shows people can start feeling better in the first one to two weeks, improving over the next few.[19] If you feel better in this time, it is likely the medication will work well for you; if you don't, give it more time and request a review of your medication with your GP within 3-4 weeks.[13]
- Almost 2 in 3 patients do not reach 'remission' with their first AD (a reduction in symptoms enough to say they don't have MDD).[20] Some patients need to try a few different ADs before they find one which works; it isn't your fault if this happens.

- ADs are not addictive – but they can cause some unpleasant side effects when stopping. Always talk to your healthcare professional about coming off ADs.[21]

Specialist mental health services

Patients are referred to specialist mental health services when their MDD is severe or complex.[13] You can be cared for as an outpatient (in the community) or inpatient (in hospital).[13]

You might be considered for inpatient care if there is a serious risk you could harm yourself or others or neglect yourself.[13]

Most inpatients are treated in a hospital or mental health facility voluntarily, but in some cases, patients are detained involuntarily. This is known as being 'sectioned'. This would only happen if you needed urgent treatment and were at serious risk of harming yourself or others.[22]

Crisis resolution and home treatment teams (CRHTs) help monitor outpatients, such as checking how you're feeling, providing practical support, and making sure plans are in place to protect you if you feel you might harm yourself in some way.[23]

If you've been through multiple treatments that haven't worked and / or your depression is life-threatening, electroconvulsive therapy (ECT) or repetitive transcranial magnetic stimulation (rTMS) might be considered.[12] These might sound alarming, but they are effective and while we don't know exactly why they work, they can improve symptoms where other treatment options haven't.[4]

05 Patients' rights and advice

You don't have to feel that you're not in control, you do have rights and choices

Patients' rights to confidentiality

All patients have a right to confidentiality in their treatment and the right to request that their medical information is not shared with others unless there is a public interest (e.g. one or more people would be at risk of harm without the information) or if it is legally required (e.g. where the safety of a child is at risk).[12,24]

Patients' rights in treatment

Patient needs and preferences should be reflected in treatment decisions where possible, in line with the 'person-centred care' the NHS aims to deliver.

You should be given advice on potential side effects, the likely timeframe until new treatments start working and the importance of taking your medication as prescribed.[12]

You should be involved in care planning, setting personal goals and identifying sources of support, and be offered a treatment review when necessary.[22] You also have the right to refuse treatment or physical examination unless you are deemed to lack capacity to consent when sectioned under the Mental Health Act 1983.[25]

Patient advice

Attending appointments is important, because delayed care means your depression may worsen and may take more time to improve.[26] MDD can cause memory problems and sleep issues[5] which means it can be easy to forget about appointments. Setting yourself reminders and opting into reminder services where possible can help you to remember and plan.

Sometimes, services like IAPT send you a letter to ask if you still want treatment if you've been waiting a long time. It's important to keep on top of your mail and respond to these as soon as possible. If you're struggling to open your mail, ask if a carer or friend can check it for you.

If you are severely unwell, you may be offered support under the Care Programme Approach (CPA) which outlines the care you require and who gives that care, as well as known risks and actions to take during a crisis.[27] The care plan should also include details of who can offer support during a crisis, such as family and carers, and a copy of the plan may be given to them, with your consent.[28]

You can create an informal care plan yourself by visiting the SANE website, or following the link in the self-help resources section on page 11.

06 Carers' rights and advice

Caring for someone with MDD can leave you feeling helpless, frustrated, and isolated. Learn about all the support and information available to you

Carers' involvement in treatment

If you're providing support for someone with mental illness you may be described as a 'carer'. Carers are usually family members, partners or close friends of the patient.[29]

Healthcare professionals can only share information with you about the person you care for if they have provided consent. If the person you care for wants you to be involved, make sure they have given consent to their healthcare professionals, so you can be involved in their care plans.[30]

It may be useful to develop a care plan with the person you care for to prevent difficulties in the event they become unable to give consent (e.g. by losing mental capacity due to being ill). You can create an informal care plan using the template on the SANE website or following the link in the self-help resources section on page 10.

Being involved as a carer helps you to collaborate with healthcare professionals. It helps to keep you informed of how the person you care for is doing, what's going on in their treatment, and how you can best support them.[30]

Carer wellbeing

Caring for someone can be very tiring and take a lot of your time. It is important you take steps to look after your own mental wellbeing.

Any carer over 18 years old can access a free carer's assessment through the NHS, to see what might make your life easier. You can access this through adult social services at your local council, or through the children with disabilities department if you're a parent or carer of a child.[31]

Your GP may also be able to help; let them know you are a carer as soon as you can so it can be recorded in your medical records. They can offer you support and advice for any difficulties you're facing and difficulties of the person you care for.[32]

If you're feeling stressed and think your own mental health might be affected, you can also self-refer to IAPT online or over the phone, or through your GP, to have an assessment and see what support they could offer. See page 10 for resources which may be able to offer you support, including a carer's assessment.[31]

07 Hope for the future

Knowledge has the power to set you free

Hope for the future: Depression research

Our understanding of depression has changed radically over time. 'Melancholia' was used to describe a range of mental health conditions in medieval times and before, thought to be caused by biological problems with 'humours' (blood, bile and phlegm).[33]

We understand depression much better these days, though we still need to know more, so we can better define the types of depression, what causes them, and how to treat them better.

Some promising avenues of research to understand biological factors and develop better medical treatments include:

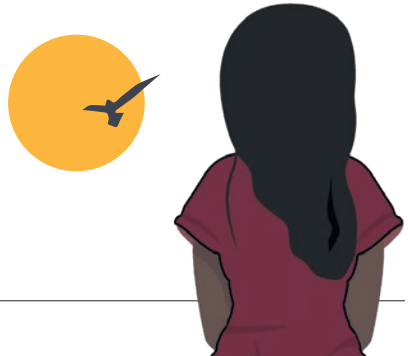
- **GENETICS: Establishing which genes contribute to depression is difficult** and is likely to take a long time, but we have discovered a few potential genes. Future progress might help to **identify who is likely to become depressed and develop treatments which target these genes,** or identify which treatments are likely to work best for some people.[5]

- **HORMONES: We know there are hormonal changes in depression,** but we need to understand how hormones change in different types of depression. We also need to understand who might benefit from hormone therapies, so we can develop effective treatments.[5]

- **NEUROPLASTICITY:** The brain works through sending signals between its different parts, using nerve cells (neurons). These signals regulate everything we do – sleeping, eating, memory, learning, mood and more. MDD can stop the brain from strengthening neurons or creating new ones, which can recover with successful treatment, but slowly. **A range of treatments are currently being developed which help the brain rapidly restore neurons, which may lead to exciting improvements in the way depression is treated.[5]**

Research is also underway to improve psychological interventions; research suggests the client-therapist relationship and the personal attributes of the therapist (e.g. being warm, empathetic) may affect the outcome of therapy more than the techniques of the therapy itself.[16]

If we understand what kind of therapist qualities work best in general, what qualities work best for particular clients, and what factors influence the therapeutic relationship in different stages of the therapy, we might be able to tailor therapies to the needs of the client and improve the training therapists receive, to better increase the chance of success.[16]



08 Resources

Helplines

SANEline 0300 304 7000 (visit **sane.org.uk** for more details); specialist emotional support, guidance and information to those affected by mental illness, family, friends and carers.

Samaritans 116 123 (Open 24 hours), jo@samaritans.org (response within 24 hours); a place to talk about what's going on with you, whether mental illness related, for suicidal thoughts, or stressful life events.

Depression information

SANE; information on depression, self-harm, suicide, research, publications and more: http://www.sane.org.uk/

Harmless; information on self-harm, including for family, friends and young people, case studies and resources: www.harmless.org.uk

Self-help

Living Life to the Full; self-help on various issues including depression, stress and anxiety, with modules for adults, young people, carers and those with long-term conditions, recommended by IAPT: https://lltf.com/

Centre for Clinical Interventions (CCI); depression workbooks, information sheets and worksheets, with similar support for other mental illnesses and difficulties: https://www.cci.health.wa.gov.au/resources/looking-after-yourself

Northumberland, Tyne and Wear NHS Foundation Trust; self-help leaflets for depression and a range of other topics: https://web.ntw.nhs.uk/selfhelp/

Mental health services and treatment

Improving Access to Psychological Therapies (IAPT); IAPT provides free talking therapies for a range of conditions including depression and anxiety. You can self-refer or ask your GP to refer you. To find your local IAPT service, visit the NHS website: https://www.nhs.uk/Service-Search/Psychologicaltherapies-(IAPT)/LocationSearch/10008

British Association for Behavioural & Cognitive Psychotherapies (BABCP); learn about CBT, how to access CBT and find a private cognitive and behavioural psychotherapist: www.babcp.com

British Association for Counselling and Psychotherapy (BACP); information on therapies, if therapy can help, and find a private counsellor or psychotherapist: www.itsgoodtotalk.org.uk

Counselling Directory; learn about counselling and psychotherapy, learn about depression, facts and figures, find a private counsellor or psychotherapist: https://www.counselling-directory.org.uk/

Information for carers

SANE; information and guidance for family, friends and carers: https://www.sane.org.uk/understanding-mental-illness/self-help-other-support

Carers UK; news, research, publications, help and advice:

Care plan template

You can access the template for an informal care plan on the SANE website to remind you and your carers of your treatments and preferences. To download an editable PDF to fill out electronically and / or print, head to the SANE website

09 Glossary & References

Low intensity: Psychological interventions, generally for people with depressive symptoms or mild-to-moderate depression. The session number and length varies depending on the intervention.[14]

High intensity: Psychological interventions, generally for people with moderate-to-severe depression, or mild-to-moderate where low-intensity interventions haven't helped. Usually 12-16 sessions lasting 50 minutes each but can vary depending on the type of intervention.[14]

CBT: Cognitive behavioural therapy, focuses on how our thoughts, beliefs and attitudes affect our feelings and behaviour, using tasks in-session and as homework to change unhelpful patterns.[34]

IPT: Interpersonal therapy, which focuses on depression as a response to difficulties in relationships, which can affect the quality of those relationships.[14]

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