

ENGAGING, STARTING, CONTINUING

Succeeding in the treatment journey: patients' perspectives



his brochure has been developed specifically for people living with depression. It has been co-created by people who have experience of living with depression who are members of Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe), a pan-European organization representing and advocating for the interests and rights of people affected by mental ill-health, and by SERVIER.

This brochure contains personal insights from people with first-hand experience of living with depression and can be read in conjunction with previous publications such as A guide to depression and its treatment and Take care and be kind to yourself available at https://www.gamian.eu/publications/.

We would like to extend our warmest thanks to all of those involved in helping us to create this brochure, including:

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### YOU ARE NOT ALONE

Globally, an estimated 280 million people have depression, that's around 5% of the world's adult population.<sup>1</sup> As such, depression is one of the most common mental health problems and is a leading cause of disability.<sup>1,2</sup>

Depression is different from usual fluctuations in mood and emotional responses to everyday life events.<sup>2</sup> People living with depression can experience feelings of being intensely sad, and/or hopelessness.<sup>3</sup> They can have little or no interest in activities and a decreased ability to feel pleasure.<sup>3</sup>

Depression can have a substantial impact on everyday life.<sup>1-3</sup> In many cases, depression is a chronic condition, and experts recommend that it should be managed as such, ie, with a comprehensive, longterm treatment plan.<sup>4</sup>

Treatment can involve medications, and/or psychological therapies, which are sometimes called talking therapies. <sup>5,6</sup> Clinically recommended treatments for depression are not discussed here. For further information regarding treatments for depression, please refer to our previous brochure **A guide to depression and its treatment** available at https://www.gamian.eu/publications/.

# DEPRESSION TREATMENT PATIENTS' VIEWS

People with depression have compared engaging with treatment to prominent personalities who are intelligent, honest, and kind. They recognize that the treatment journey can draw out hidden depths of resolve and courage.

Pippi Longstocking, the hero in children's books by Swedish author Astrid Lindgren, because of her honesty about joy and sorrow.

Inspector
Jacques Clouseau,
French police
detective in
The Pink Panther
series, because
he is honest
and kind.

If treatment for depression was a famous person who would it be and why?

The Moomintrolls, a family of fairy-tale trolls in the books and comic strip by Finnish illustrator Tove Jansson, because they have hidden depths.

The English private investigator
Sherlock Holmes, created
by Arthur Conan Doyle, because
he is smart and always
solves the problem.

<sup>1.</sup> World Health Organization. Depression. Key facts. September 13, 2021. Accessed November 11, 2021. https://www.who.int/news-room/fact-sheets/detail/depression.

<sup>2.</sup> World Health Organization. Depression in Europe: Facts and figures. Accessed November 11, 2021.

https://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2012/10/depression-in-europe/depression-in-europe-facts-and-figures.

<sup>3.</sup> American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders: DSM-5. 5th ed. Washington, DC: American Psychiatric Association Publishing; 2013.

<sup>4.</sup> Unützer J, Park M. Strategies to improve the management of depression in primary care. Prim Care. 2012;39(2):415-431.

<sup>5.</sup> National Health Service. Clinical depression. December 2019. Accessed November 11, 2021. https://www.nhs.uk/conditions/clinical-depression/.

<sup>6.</sup> Qaseem A, Barry MJ, Kansagara D. Clinical Guidelines Committee of the American College of Physicians. Nonpharmacologic versus pharmacologic treatment of adult patients with major depressive disorder: a clinical practice quideline from the American College of Physicians. Ann Intern Med. 2016;164(5):350–359.

# ENGAGING, STARTING, CONTINUING

Someone can, and will help, if I ask for it.

It's not helpful to wait to have a conversation to improve mental health; having a doctor who I could trust and who understood me was really important. It was important to be open and honest about my symptoms and not to blame myself for my depression...

I wouldn't blame myself for having a chronic illness such as heart disease, so why blame myself for having

depression?

Support groups that bring together people who are going through or have gone through similar experiences and understand the true impact of depression are priceless. The first time I met people who shared similar experiences changed the way I viewed my condition and allowed me to be more accepting of the way I felt.

Entering into a dialogue with your health care professional is an important part of the treatment process. The importance of honest and open discussions should not be underestimated and allows you to remain active in your treatment.

Just as with treatment for any health condition, for people with depression, engaging in, starting, and continuing treatment can be a complicated process involving a series of often frightening or overwhelming decisions:<sup>1</sup>

- The individual first needs to **recognize** that there is a problem and then decide whether to consult a health care professional.
- The health care professional must then be able to **diagnose** the health problem and may propose a **treatment or management plan**.
- The individual must then decide whether to **start treatment** and subsequently, whether to **continue** it.

Quotes and insights reflect the experiences of people living with depression and do not necessarily reflect medical and scientific evidence or practice.

1. Rush AJ, Thase ME. Improving depression outcome by patient-centered medical management. Am J Psychiatry. 2018;175(12):1187–1198.



Being open and honest is an important step toward getting help and sustaining the motivation to keep going with treatment, even when faced with challenges.

Trust in people and the whole process is important; an honest and open dialogue with an understanding health care professional can help you manage symptoms and expectations.

Friends, family, and support groups play a critical role in helping and supporting as you navigate along the treatment pathway.

Meeting people with similar experiences is comforting and provides reassurance that you are not alone.

## **ENGAGING IN TREATMENT**

When I finally understood that it wasn't fair to feel that way, that's when I decided to get some help.

We all lose motivation at times, but we get back up and so can you. Being able to recognize the positive impacts of treatment, while also accepting that it could be a long journey, helped me to take the first steps.

My motivation for treatment was wanting to live my 'best-life,' not necessarily going back to 'normal,' but I didn't want to feel that bad.

KNOWING
HOW LONG THE
TREATMENT
WILL LAST

PEOPLE GETTING

RECOGNIZING THAT
THE FUTURE CAN

**RESPONSIBILIT** 

INFORMED

REACHING A LOW POINT

BE BETTER

SUPPORT AND
REASSURANCE
FROM HEALTH CARE
PROFESSIONALS

UNDERSTANDING AND ACCEPTING DEPRESSION

**UNTIL THE BENEFITS** 

**WILL BE SEEN** 

SUPPORT AND REASSURANCE FROM Family and Friends

Some people with depression may not want treatment and experts recognize that several factors may contribute to this, including: a lack of belief in the benefits; concern over the cost; feeling the process is too complicated; and worrying about possible side effects.<sup>1</sup> People can also be reluctant to engage in treatment because of the stigma associated with seeking mental health help.<sup>2</sup>

The treatment journey may involve contact with numerous health care professionals, who may or may not recommend treatment that the person with depression considers helpful. Negative experiences may result in an individual not wanting any further treatments.<sup>3</sup> However, a recent survey from the World Health Organization (WHO) has shown that people who remain engaged and persevere with different types of therapies will find a treatment that they consider helpful.<sup>3</sup>

Quotes and insights reflect the experiences of people living with depression and do not necessarily reflect medical and scientific evidence or practice.

- Rush AJ, Thase ME. Improving depression outcome by patient-centered medical management. Am J Psychiatry. 2018;175(12):1187–1198.
- Corrigan PW, Druss BG, Perlick DA. Impact of mental illness stigma on seeking and participating in mental health care. Psychol Sci Public Interest. 2014;15(2):37–70.
- 3. Harris MG, Kazdin AE, Chiu WT, et al; WHO World Mental Health Survey Collaborators. Findings from world mental health surveys of the perceived helpfulness of treatment for patients with major depressive disorder. *JAMA Psychiatry*. 2020;77(8):830–841.

KEY INSIGHTS

Engaging in treatment and starting the journey can be a challenging and personal process.

Motivation to take responsibility for your health and to look toward a brighter future are important factors for engaging in treatment.

Engaging in treatment involves help, support, and reassurance from many different people including health care professionals, family, and friends.

MOTIVATION FOR TREATMENT

### STARTING YOUR TREATMENT

Trust and believe in the treatment and everyone involved.

Don't cut
people out of
your journey,
they can help
you decide where
you want to go
with the
treatment.

Having the support of peers, friends, and family, and being able to seek support online to share experiences also helps when deciding to take the first steps with treatment.

Being able to see the potential for a positive impact, while also knowing it takes time and patience to see results, can help you move toward seeking treatment. A large proportion of people with depression do not take the first step and initiate treatment.¹ Research shows that, overall, more than 30% of people with depression do not start their treatment.² Around a third of those referred fail to attend a first psychotherapy visit and one in four people prescribed a first-time antidepressant either do not take their medication or only continue with it for a short time.³.4

It is known that for many people with depression, there are numerous potential barriers to starting treatment.<sup>5</sup> These barriers can be daunting and include attitudes and beliefs about depression and its care.<sup>5</sup> Once a treatment has been recommended it is important to begin it as early as possible. Research confirms that recognizing depression early and then getting started on treatment is crucial for better long-term outcomes.<sup>6</sup>

For people with depression, making the decision to begin treatment may involve many difficult considerations.<sup>1,2</sup> Taking the first steps toward treatment requires collaboration, help, and support from health care providers, family, and friends.

Quotes and insights reflect the experiences of people living with depression and do not necessarily reflect medical and scientific evidence or practice.

- Moise N, Falzon L, Obi M, et al. Interventions to increase depression treatment initiation in primary care patients: a systematic review. J Gen Intern Med. 2018;33(11):1978-1989.
- 2. Rush AJ, Thase ME. Improving depression outcome by patient-centered medical management. Am J Psychiatry. 2018;175(12):1187–1198.
- Simon GE, Ludman EJ. Predictors of early dropout from psychotherapy for depression in community practice. Psychiatr Serv. 2010;61(7):684–689.
- Van Geffen EC, Gardarsdottir H, van Hulten R, et al. Initiation of antidepressant therapy: do patients follow the GP's prescription? Br J Gen Pract. 2009;59(559):81–87.
- 5. Nutting PA, Rost K, Dickinson M, et al. Barriers to initiating depression treatment in primary care practice. *J Gen Intern Med*. 2002;17(2):103–111.
- 6. Kraus C, Kadriu B, Lanzenberger R, et al. Prognosis and improved outcomes in major depression: a review. *Transl Psychiatry*. 2019;9(1):127.



Having trust and a belief in health care professionals who understand depression is important when taking the first steps; this helps people talk openly and honestly about their symptoms and to have trust in the treatments being offered.

Having reassurance from health care professionals
helps people to have confidence in articulating their expectations or motivations to get better, stay happy, and have a good life balance.

Accepting that treatment may be long term and the possibility of living with it for several months is important if you want to see an improvement.



### **CONTINUING YOUR TREATMENT**

Things did get worse at first, but then they started to improve. That's when I realized it was important to continue with my treatment.

Even when you think that you no longer need professional help, it is helpful for your health care professional to see you when you are feeling better, because the changes are then more obvious to both you and your health care professional if things should become more difficult.

I always understood this was not a 'quick fix' and I had to keep going.

Remind yourself that treatment not something holding you back.

is a way of helping you move forward,



Understanding

depression

and the importance

of treatment

are central: knowledge is a

valuable tool.

For any health condition, sticking to a treatment plan is vital for treatment success.<sup>1</sup> It has been shown that for people with depression, continuing with treatment is crucial for better outcomes.<sup>2</sup>

Development and approval of any treatment modality is a complex process which involves scientific studies. To get the most benefit, it is important to continue your treatment as recommended by your health care professional.

Unfortunately, continuing treatment can be challenging. According to research, up to 50% of people with depression do not complete the first 6 months of treatment; among those who do stay in treatment, more than half do not take their treatment as prescribed or scheduled.<sup>3</sup> In a separate study, up to 50% of those referred for psychotherapy drop out before a second visit.4

Being able to keep the conversations going with understanding health care professionals, family, and friends, who keep listening and offering support helps people living with depression to have trust in the treatment process. This enables them to better manage their symptoms and expectations so that they are more likely to keep going on their treatment path.

It can feel very challenging to continue with treatment when expectations are not met, so it is really important to **keep seeking** 

help and support.

Feeling better is a good motivator. Learn to enjoy small moments of not being depressed, even if these feelings are fleeting.





- 2. Solmi M, Miola A, Croatto G, et al. How can we improve antidepressant adherence in the management of depression? A targeted review and 10 clinical recommendations. Braz J Psychiatry, 2021:43(2):189-202.
- 3. Rush AJ, Thase ME. Depression outcome by patient-centered medical management. Am J Psychiatry. 2018;175(12):1187-1198.
- 4. Simon GE, Ludman EJ. Predictors of early dropout from psychotherapy for depression in community practice. Psychiatr Serv. 2010:61(7):684-689.



### FURTHER INFORMATION AND SUPPORT

Information, knowledge, and support can help you manage daily life with mental health problems. Follow these links to useful websites and resources for further information and support.

#### GAMIAN-EUROPE website

https://www.gamian.eu

#### National Institute of Mental Health

https://www.nimh.nih.gov/health/topics/depression

#### Mental Health Europe (MHE)

https://www.mhe-sme.org/who-we-are-2/

#### Mind

https://www.mind.org.uk

#### WHO

https://www.who.int/news-room/fact-sheets/detail/depression

### MANAGING DEPRESSION: A 3-STEP APPROACH

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Succeeding in the treatment journey: patients' perspectives

Do not change or stop your treatment without advice from a health care professional, such as your referring doctor.

If your symptoms worsen, please consult a health care professional, such as your referring doctor.





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