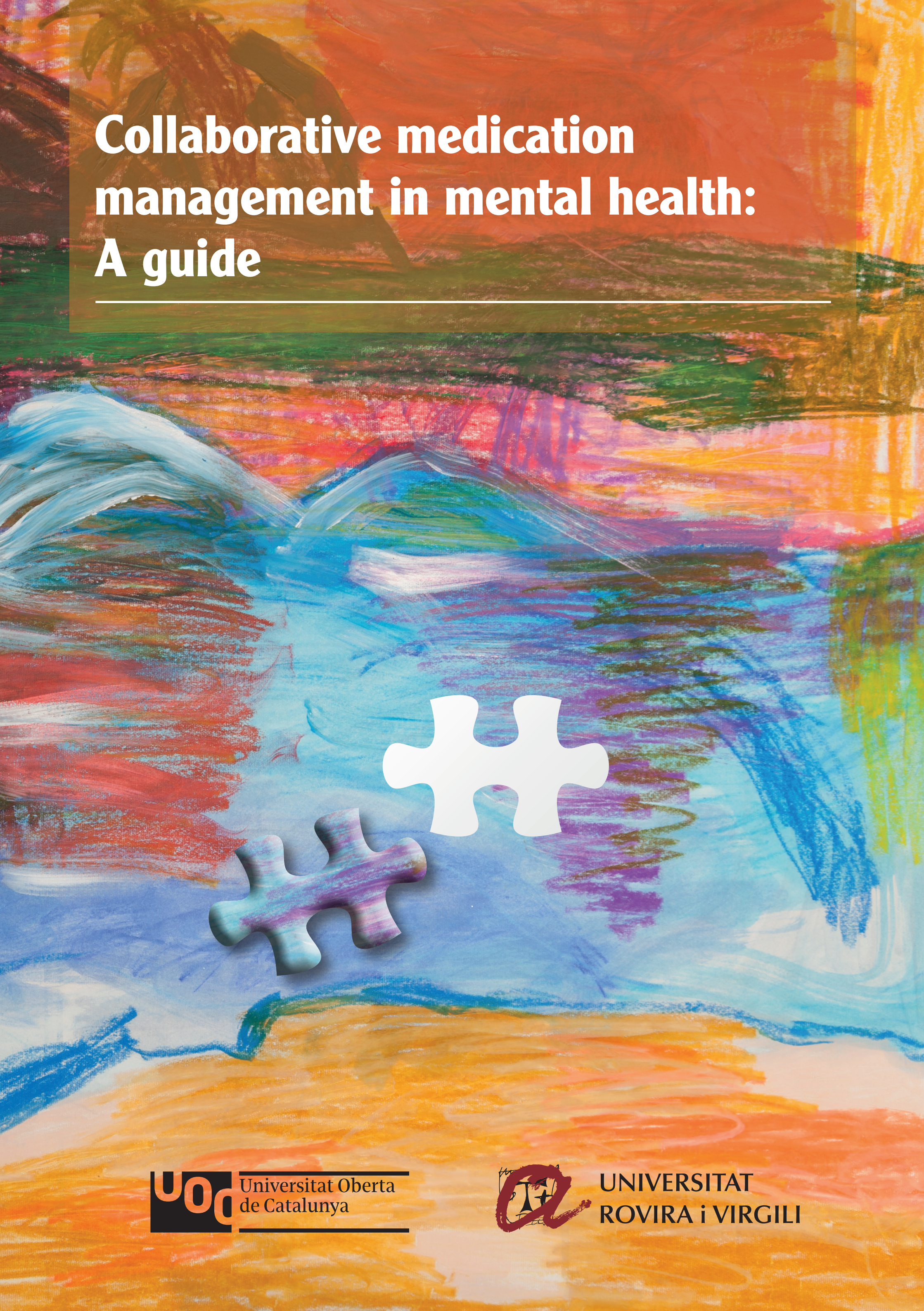
Collaborative medication management in mental health: A guide



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Revision of the chapter "Exercising your mental health rights": Mª Àngels Porxas Roig

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Index

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- CSMA Badalona II
- Club Social Aixec SCCL

On possible conflicts of interest and ethical considerations

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No funding was received from any pharmaceutical or healthcare company in the production of the guide.

The research team received external independent advice and supervision from the **healthcare ethics committee of the Fundació Congrés Català de Salut Mental** (FCCSM) (http://www.fccsm.net/comite-detica-assistencial/), and the research on which the guide is based was approved by the Universitat Oberta de Catalunya (UOC) ethics committee.

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Introduction

What is the Collaborative Medication Management Guide? (CMM Guide)

The CMM Guide is designed to open up a space for reflection and dialogue on the role psychiatric medication plays in people's lives. It was written by people who have experienced mental health problems, their family members and care givers, and mental health professionals and researchers.

The CMM Guide starts by recognizing the rights of people with a mental health diagnosis, and advocates for their position as co-protagonists in care processes.

We invite readers of this Guide to reflect on their own personal journey, taking into account the necessary connections and relationships that support us as subjects and that provide the basis for our projects to live autonomously. Our proposal is based on an understanding of autonomy as the capacity a person can develop to satisfactorily manage their social network, rather than an individualist conception of the term.

A participatory action research project

Origin and methodology

The origins of the collaborative medication management guide lie in the Gaining Autonomy in Medication (GAM) Guide. The GAM Guide initiative was developed in the early 1990s in Quebec (Canada) by research teams at the Université de Montreal in collaboration with civil society associations, especially users of mental health services and their *advocacy groups*. The GAM Guide is now recognized as good practice by Quebec's Health and Welfare Commissioner. In recent years, the experience has gained further stimulus through its implementation in Brazil within the framework of the Alliance internationale de recherche universités-communautés, Santé mentale et citoyenneté (ARUCI-SMC) http://www.aruci-smc.org/fr/

In Catalonia, the project for the collaborative medication management guide was based on qualitative research carried out by a team of professionals from the Universitat Rovira i Virgili (URV) and the Universitat Oberta de Catalunya (UOC). Users of psychopharmaceuticals participated in the research as members of the research team, along with family members, carers and professions.

Project website: http://gcmproject.org

Users of psychopharmaceuticals were present throughout the entire project, initially as informants and participants in the interviews and focus or discussion groups, but also as protagonists in initiatives such as the Laboratori FerRecerca AMB, the purpose of which was to oversee the whole process and co-manage production of the materials. The Laboratori FerRecerca AMB was set up as a space for users, professionals, family members and researchers to put forward contributions and assess impacts, and also serves as an advisory board. The Laboratori aims to represent civil society, proposed to provide social control over the research, and was present in supervising the process from start to finish.

This first version will be evaluated and revised after its implementation as a future pilot project. We intend to produce several shorter guides addressed to specific groups, such as professionals, family members, carers and facilitators of possible groups.

A personal guide, a collaborative guide

The Canadian and Brazilian versions of the GAM Project adhered to the personal guide format essentially aimed at users of psychopharmaceuticals. In this version, we want to maintain the focus on people who are affected by a situation of mental distress, but at the same time open up the tool to include the voices of others involved in the process: carers, family members and professionals.

The Collaborative medication management guide is initially presented as a process or a proposal for personal reflection on the pharmacological treatment a person is following, the state of their health and the environment in which they live. Additionally, we believe their social relationships and support systems must also be taken into account, since we understand the importance of approaching autonomy as something that goes beyond individuality, and that comes closer to the shared management of pain and distress.

The guide therefore provides an opportunity for everyone involved to be heard in this possible dialogue. This is one of the aspects that differentiate our project from previous experiences in other countries. Including professionals and the people in an individual's care network is intrinsic to our research. On the one hand, the care network, and especially families, has traditionally held a position of responsibility in care, but at the same time their presence in the hegemonic or conventional care spaces has been restricted. On the other hand, we consider that the voice of professionals who want to critically reformulate and rethink their practices must also be recognized and incorporated.

What you will find in the Guide

- ✓ Useful information on rights, and on medications and their side effects.
- ✓ First-person experiences reflecting on these issues. We include quotations and short accounts from the participants (informants) in our research.
- ✓ Questions to stimulate reflection and help form a personal opinion and position about the medication.
- ✓ Tools for creating a shared space in which to talk about mental health medication.
- ✓ References to additional sources of information.

Who is the Guide for?

This Guide is designed to be used by people who have experienced mental suffering and have received and taken psychopharmaceuticals as a therapeutic measure. It can also be used to stimulate dialogue and debate on this treatment with the other people involved.

How to use the Guide

The Guide can be used in different ways, depending on the reader's interests and preferences and their personal and social circumstances. It does not, however, aspire to be an exhaustive manual on the complex subject of pharmacological treatment. It proposes a series of questions to provoke reflection on this subject and open up a channel for thinking about new ways of approaching it through co-management. The Guide also contains first-person narratives and accounts selected from the material gathered in our research. We hope that these extracts will help to stimulate reflection and illustrate the subjects proposed in the Guide.

The Guide does not have to be read from beginning to understand all its contents. Each chapter is organized so readers can refer to the section they find most useful for their circumstances at any given moment.

The Guide can be used individually or in groups to reflect on the questions posed, or to read topics of interest or other contents referred to.

For group work, we recommend that all the participants first discuss and agree on how the group should be organized: how many people can participate, for how long, what rules can or should determine which new people can join, and who should be the group facilitator or leader. The previous experiences in other countries suggest various possibilities. For instance, the task of leading or facilitating the group could fall to a professional, although not necessarily an expert in medication, or to someone who has had experience of both taking medication and leading groups.

The Guide may be used to work in different spaces, such as therapeutic facilities, self-managed centers, “first-person” organizations or associations, etc.

Whatever the case, it is a personal task that requires time and a minimum of self care due to the complexity of the topic we are dealing with.

Principles or starting points

- **Recognizing different kinds of knowledge.**

  The CMM Guide is based on recognizing different types of knowledge: not only professional knowledge, but also the knowledge brought by other people involved, such as users, family members and carers.

- **Recognizing different experiences.**

  The experience of pharmacological treatment is subjective and personal. Taking medication can have different meanings for different people.

- **Dialogical perspective.**

  The CMM Guide approaches the question of pharmacological treatment through dialogue. It encourages reflection on a range of possibilities someone might consider, all of which are conceived of as actions to be undertaken in collaboration with others.

- **Recognizing rights.**

  The Guide pursues the recognition of the rights of those affected with regard to their treatment: the right to information, the right to consent, to take part in their treatment, etc.

Precautions to bear in mind

It can be dangerous to stop taking psychiatric medication and change the dosage without the supervision of a qualified healthcare professional and without taking all the necessary precautions.

The CMM Guide provides readers with accurate information that can increase their capacity for negotiating and taking decisions about their medication.

Chapter 1.
Reflecting on your own experience

We suggest beginning by thinking about some personal aspects related to your lived experience, the pain or distress you may have felt over time, the treatment you have taken and how you manage or have managed the worst periods of suffering. This exercise can help us to connect with our desires and also our limitations, and to recognize the personal resources that we can draw on if we feel ill.

This is the moment to (re)think the role medication has in your life, and also what it symbolizes, in other words, what it means to you and to your environment.

The exercise we suggest here contains some particularly sensitive questions and issues that you might find uncomfortable or even painful. You might wish to read it together with people who you trust and who can support you while you think these questions through—perhaps a friend, your partner, a family member or a professional.

You do not have to answer all the questions before going on to read the rest of the Guide. It is important, however, to approach this first part as a self-reflection exercise that will lay the foundations for the personal tasks that come later in the Guide.

« So, most of all a person knows their own body. That is, maybe they can't know the illness and the scientific side very well. But a person knows their own body and knows what makes them feel good and what makes them feel bad. So, when a patient tells you, "No, it's like … well, I wet myself a bit…" or "You know what? I dribble" Or, I don't know, I can't explain it… "Like I feel ill, I feel really ill, I feel tired, I feel like I can't be bothered…" I can't explain it. That the patient knows their body and knows when it makes them feel ill. »

(user, female)

« Starting from what we don't know about the human mind. That's a challenge. What is a problem is dealing with something we don't understand as though we do understand it. That's how you end up seeing just symptoms. This affects us as well as the affected person and the professionals. It's not just a lack of information, it's a problem that you don't understand, but most of the time the professional doesn't understand either. If they could begin by recognizing this like we do, I think they would achieve much better outcomes. »

(family member, father)

1.1. Reflecting on your own life and personal/social position

Some questions about self care

- In what ways do I care for myself or try to care for myself?

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- What are my usual sleeping habits?

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» ...and eating habits? (amount, quality, variety...)

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» Am I taking any kind of harmful substances at the moment? (for example, alcohol, drugs...)

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About my living conditions

- What sort of place do I live in? (I have my own home, I live in a residential facility...). Do I share this space with anyone else? (family, friends...)

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- What are my financial circumstances?

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- What are my favorite everyday activities?

- How much do I participate in social initiatives? (taking part in associations, social organizations, volunteering...)

About my personal relationships

» What about my intimate and personal life, my relationships? Who are my friends, partner...?

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» Who do I feel closest to, who do I trust most?

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- What about my emotional-sexual life?

- If in a relationship: What is my life like with this person? Do I have an active sex life? How do I feel about it?

» How do I feel, in general, when I relate to other people?

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1.2. Reflecting on your experience with discomfort and pharmacological treatment

> « I’ve been on medication and I’ve been off medication and, well, it’s a different life. You have control over your thoughts, you have stability, both for the hallucinations and emotional stability…, because being satisfied with your life, being contented, that gives you things that… before you were angry at the world, I was mad at myself, in the end, I used to say, “what have I done to deserve this?” »
>
> (user, male)

» How am I feeling at the moment?

» What discomfort(s) do I have/am I feeling?

- What difficulties do I face in dealing with this discomfort?

- What are my strengths in dealing with this discomfort? What personal strategies do I have for managing it?

Strengths

Strategies ....

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» Who helps me when I'm feeling ill? (professionals, other people with a mental health diagnosis, family members, volunteers at an organization)

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- What treatments am I following? (psychological, pharmacological, others...)

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- If I am taking pharmacological treatment, what sort of relationship do I have with the medication? (I feel comfortable with the treatment, I don't like taking tablets, it conditions some thing(s) in my life...)

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- Why did I start taking neuroleptic/antipsychotic medication? (examples: because I wasn't sleeping well, because I was having strange feelings...)

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- Has the medication responded well to my symptoms? YES/NO. Why do I think this is so?

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» What’s my general physical health like?

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» Have I noticed any adverse effects caused by the medication? YES/NO. What are they? and how have they affected my life?

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1.3. Personal management of discomfort. Recognizing crises and being prepared for them

Personal management of discomfort and possible crises

» What do I feel when I feel ill? How do I identify it? (examples: how do I manage anxiety, fears...)

Decisions and taking a position when managing a crisis or a situation of intense suffering

» Who do I prefer to talk to?

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» What do I do? Am I okay about being admitted into hospital/a clinic? Have I thought about other possible options?

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- What support do I feel I have? Who do I most trust to ask for help in a situation like this?

- Who would I like to be with me in a situation of serious distress or a crisis? Why?

» And is there anyone I don't want with me? Why?

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You can also consult...

Chapter 2. Social and family network

Chapter 7. Autonomy and negotiation

1.4. Recognizing needs, desires and projects

As individuals, we can have a wide and varied range of desires and needs. In this section we suggest some questions to stimulate this self-knowledge and help you recognize your own desires, needs and possible future projects. The idea is to think about what we want to achieve as individuals and to evaluate our capacities and potential for reaching those goals.

At the same time, through the CMM Guide we want to stimulate reflection on the impact that pharmacological treatment may have had on the intimate and personal development of your life, whether or not it has contributed, helped, or raised barriers, etc.

Whatever the case, thinking and reflecting on your own personal development can be a long, sensitive process. It is important to take all the time you need to do this, and to recognize beforehand that it will not be an easy subject to face.

» What are my needs? Which needs do I prioritize or consider to be most important?

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» Do I have a project in mind that I want to see through? What is it?

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» What are my desires?

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- Have I felt that the medication has cut me off from my emotions and desires? YES/NO. Why?

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1.5. Some alternative proposals for managing crises

Advance planning for mental health situations and advance directives

Advance planning of mental health decisions. *Guia de apoyo para profesionales y personas usuarias de los servicios de salud mental*. Junta de Andalucía.

https://www.easp.es/?wpdmact=process&did=MTM0LmhvdGxpbms=

Manual per a la Recuperació i Autogestió del Benestar. Activa't per la salut mental. Federació Salut Mental Catalunya i Federació Veus.

https://activament.org/es/2021/manual-recuperacion-autogestion-bienestar/

You can also consult…

Chapter 7. Autonomy and negotiation (see “Care agreement” section)

Chapter 2.
Social and family network

Medication not only affects us physically; it also has a particularly strong impact on our subjectivity and social relationships. This impact is ambivalent and contradictory. Many people explain that their social lives are affected by the adverse effects of the medication, such as emotional numbness, apathy, listlessness, slowness, etc. Others report precisely the opposite: the medication enables them to function better and therefore redress the social impact caused by the disorder itself, although people in this second group are almost always taking very controlled minimum dosages. We must therefore identify which criteria we are using to measure the difficulties people with a diagnosis have in their social relationships and how central a role medication plays in them.

In some families, medication can intervene in relationships by making the person feel cared for and supported, but in others, they may feel controlled and monitored. It is important to be aware of how central the diagnosis and treatment is in family relationships. The family cannot, and should not, unilaterally take on all responsibility for caring without the participation of the person affected. The person with the diagnosis, as the recipient of care, must be able to participate in structuring their care, which involves both taking decisions, and responsibility for self care and the care others give. For this reason, **intra-family situations should be** analyzed from a gender perspective in order to find more equitable and collective care solutions together.

Likewise, **professionals** must be able to collaborate in networks to organize care and establish the idea of teamwork, by engaging not only health professionals, but also other key individuals such as friends, partners, family, alternative social networks, etc. When we talk about care, therefore, we do not mean a two-way exchange between two people (care giver/care recipient) but a broader, collective framework of different agents and levels.

Some first-person association networks or activist movements encapsulate this idea of collective care. Some people who suffer with their mental health describe how their lives changed dramatically when they discovered groups such as these, in part because they were finally able to talk about their experiences without being judged. Instead of facing high levels of social isolation, they become part of a broad social network. These networks therefore perform a significant care function that must be recognized and encouraged. Social (re) connection should be a central part of any treatment because it stimulates change toward a better state. In the professional context, this means introducing collective care into practice.

Whatever the case, the network developed around the person must not be stifling or isolating, but should offer a space where they feel able to take decisions, and at the same time supports and accompanies their main caregivers. For this to happen, caring must be negotiated and agreed collectively, a process we call the care agreement. These agreements do not appear spontaneously, however; they must be developed together with the support of professionals. The aim of the agreement is to find an arrangement between all those who live with the person in mental pain or suffering, and to prioritize their choices and define the support and responsibilities when situations of conflict and/or disagreement arise. Paula Tomé gives this example:

> « The first of these agreements was with myself, to learn to separate the real from the poetic, the habitual consciousness (that which coincides with the consciousness broadly accepted by others) and the delirious consciousness. Separating them does not mean that the latter disappears, nor that the self-referential ideas or psychotic thoughts go away. What I mean is

> that I identify them as what they are. My friends and partners helped me enormously in making this distinction, especially when I managed to lose my fear of expressing them. Freedom of expression is invaluable in those states, finding people with whom you can express yourself without censure, without the fear that they might stigmatize or judge you, is a gift that should be a right. »

(Tomé, 2014:18)

Paula Tomé describes how she uses intervals between delirious experiences as prevention time, to update her care agreements with her network:

> « Work out what happened, how I felt, how I explain it, and especially, what I want or don't want if it happens again. At the same time, my friends talk about their side of the experience, their feelings, their concern, their evaluations... and the agreements come out of these exchanges. »

And essential to these agreements is trust, she says:

> « Many of the ingredients of these care agreements are first established in periods without delirium, and are picked up later during the delirious period. This strategy always worked well for me; it has a powerful preventive component, it's like laying the foundations, beforehand, for a "bearable" delirium, and by bearable, I mean with as little psychotic disturbance as possible. »

(Tomé, 2014:18)

You can also consult...

Chapter 7. Autonomy and negotiation (see “Care agreement” section)

2.1. Questions for thinking about the family

- To start with, it’s important to think about whether I want my family members to be part of my care process. YES/NO. Why?

- If the answer is yes, how can I involve my family in my care process?

- Which of my family members would I like to participate?

- What approach should my family take when I feel ill? And to the treatment?

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In the family's relationship with the treatment, what do you think about…

- How the carer or family member can strengthen the autonomy of the person following treatment?

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» How do you think family members or carers can be properly integrated in the process of treating the person with the diagnosis?

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« I've been lucky with my family. The family, in this case my mother and two brothers. Knowing how to be open, not judgmental, all that misery that suddenly pours out of a relative, right? That it can be experienced as a personal thing, and they supported me enormously and sometimes they got it right more than others, but everyone's learning and no one knows anything. About how to deal with this. No one knows what's best when you're taken by surprise by episodes like this or crises like in this case that were really powerful, something that's very, very difficult to control [...] Support, feeling loved and feeling that they are fighting for me and that we're all in this together. Then with my wife because she supported me, she didn't leave me, but many things got broken. Maybe this situation was beyond her control, or she didn't know how to face it or how to be strong there, and even though she stayed with me I feel she was overwhelmed, she felt overwhelmed and sometimes that makes me feel guilty when I wasn't to blame at all... »

(user, male)

> « The truth is that at the beginning the user is very, very ill and very lost, and the family is equally lost. It's a drama that only those who've experienced it know. So you go along with what the doctor says. The patient doesn't want to take the medication. It was a massive effort to get him [her son] to [X] center because he was feeling really ill. You take medication to feel better, but if you take it and you feel worse? How do you explain to your son that he has to take it? »
>
> (family member, mother)

> « Medication yes, but as a support, not as an end in itself. I think this first moment conditions your first view of everything. It made me suspicious of the professionals who didn't tell me why my son was dribbling like that. I don't want a professional that just writes out a prescription, I want to discuss [things]. My son isn't well now and I'm the one defending the reduction of his medication. »
>
> (family member, mother)

2.2. Reflecting on other possible social care networks

Isolation and loneliness are often sources of suffering that compound and increase the pain the person already experiences as a result of their condition. Here, social networks can play a supporting and caring role during times of greatest distress or pain. In the next section we suggest you think about your own social network, who it includes, what type of help have they given you or could give you, and who you think should be part of the network if you do not yet have one.

» Who are the people I usually relate with?

» Thinking about those relationships, how much do we trust each other? do they help me to solve daily problems? could they help in a crisis situation…?

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« In my case, it's my parents and I think I'd listen to them because I have the capacity to decide; that said, my partner is the one who lives with me a lot of the time, if I've told him I'm reducing my medication, he's replied, "be careful!", because he suffers the consequences more if I have an episode. Both of us keep a careful eye on it, because I know myself very well and for me he's my family and I take his opinion on board. »

(user, female)

Associations and experiences of activism and participation

The network of people who can offer care when we experience situations of distress or pain may also include members of associations or spaces you may take part in. For many people, these are one of their main sources of support. The following questions ask you to think about any such spaces in your life (participation processes, organizations, associations you take part in):

- What organizations (associations, participatory spaces) do I know? Which ones have I ever participated in?

- Which organizations or spaces would I turn to if I was feeling ill?

Designing/defining an ideal space for participation/expression

- What would this space be like?

- Do I know of any spaces that function like this model or could adapt to it?

- Have I ever taken part in any such spaces? YES/NO. Why?

> « Well, let's say that the services, the community is better prepared, more advanced. There is more information about mental health, more interest..., and on the whole question of stigma there have been changes. There are more places I can refer people to, there's a bigger network. There's Activa't, then those at Red Sin Gravedad. They organize mental health prevention activities, but they don't see themselves as a mental health service. They don't ask for reports, or ask people what's troubling them. They stimulate activity. »
>
> (professional, social worker)

(Some) spaces for meeting/activism

- Community resources
- Community centers, social centers...
- Associations with specific interests: social, cultural, political...
- Sports clubs and leisure centers...
- Alternative therapy spaces
- Formal and informal training centers (self-run)
- Mental health rights defense groups
- Spaces for exchange: time banking, spaces for bartering and repairs
- Community radios
- Information services: Barcelona City Council Care Office. Social Services departments, etc.

Chapter 3.
Relationships with professionals

The relationship between professionals and users will be decisive in the subjective experience of the pharmacological treatment. The basis of good treatment begins with a good personal manner, a relationship of trust in which professionals and the people being cared for can put forward their arguments from a position of mutual recognition. In contrast, an asymmetrical care relationship may lead to unc weaker position (Leal, 2006; 2009).

> « Interviewer: If I were a psychiatrist, how could I gain your trust?
>
> Informant: It's impossible, because just the thought that you have the power to put me in a psychiatric unit sets me against you. »
>
> (user, female)

3.1. Organization of services

Mental health care teams generally include professionals from psychiatry, clinical psychology, nursing, and also from social fields such as education and social work, social psychology, occupational therapy, home-care workers, social integration and administrative personnel.

In this team of professionals, which may include other practitioners in some services, the doctor or psychiatrist is in charge of and ultimately responsible for the pharmacological treatment. However, a large proportion of the professionals interviewed for this research referred to the importance of teamwork in questions of medication, as members from each discipline can attend to different aspects that help to give the person more information and support through the treatment process.

The first access to the health system for someone who wants to discuss their mental health or who is experiencing a situation of mental distress may be through their primary health care center (PHCC), an adult mental health center (AMHC) or, in the case of young people under the age of 18, a child and adolescent mental health center (CAMHC). Some people may also go straight to a hospital emergency department because they need immediate attention, from where they could be referred to a specific center or service, which may or may not be one of those mentioned above. This will depend on factors in each specific situation, such as the suitability of the service or the resources available in the region, etc. If you have experienced a situation of mental distress or suffering, you may have initially turned to one of these services for a consultation or to seek help.

Other care resources are also available, such as day hospitals, rehabilitation services or community care centers, job placement services, or other facilities with more direct community interaction and participation such as social clubs, etc.

Below we list some **websites** with **information** on mental health care **resources and services**. This is not an exhaustive list, but it may help you to begin looking for the appropriate resources for you.

Atenció a la salut mental i addiccions (Mental Health and Addiction Care). CatSalut. Servei Català de la Salut

https://catsalut.gencat.cat/ca/serveis-sanitaris/atencio-salut-mental-addiccions/

Mapa de Recursos en Salut Mental a Catalunya - Fundació Salut Mental (Map of Mental Health Resources in Catalonia - Mental Health Foundation) Catalunya (SMC)
https://www.salutmental.org/la-salut-mental/mapa-recursos-salut-mental/

Confederación Salud Mental España (Mental Health Confederation, Spain)

https://consaludmental.org/

3.2. Teamwork

Professionals in the public mental health care system normally work in interdisciplinary teams that often include a dialogue-based component or perspective. This system brings together a range of viewpoints to consider and reflect on mental health problems in a holistic way, and differs from multidisciplinary systems, which are usually a set of disciplines functioning in a linear manner.

Bearing in mind that team members' training, positions and personal values will vary, decision making can sometimes be highly complex. Teamwork often requires teams to be open-minded, flexible and willing to listen; it calls for mutual recognition among the professionals involved, and between them and the people they are caring for.

Beyond the internal work in the team, external alliances should also be forged across the network. These are significant professionals in other areas with whom users also have contact and who can support them when needed, for example, an educator from another organization, a nurse at the primary health care center, etc. It is therefore important to incorporate the preferences of the person affected into the care process in order to establish a new, broader network culture.

Although the psychiatrist is generally understood to be responsible for administering and monitoring pharmacological treatment, other professionals working in care settings, such as nurses, psychologists and social workers, also build connections and act as information channels. This care work often goes unrecognized or is regarded as inferior or lower down the disciplinary hierarchy, but nonetheless it is an additional and highly valuable source of knowledge in the development of the treatment process.

> « But yes, working in mental health is like part of the treatment, so I, without understanding the medication, how it works, what effect it has, it's something we deal with in family intervention. If they're taking the medication, if there are any problems. It's a subject that comes up or you ask about, and a lot of patients

> also mention it. As it's a combined treatment, we try, with the psychiatrist, to make sure the nurse sees them, and I see them, and we alternate with each other. And they might come, and they know very well all three of us are from the same team, and say, "I'm feeling dreadful because I've got a problem with the medication". So I'll say, "I'm not a doctor but I can still help you", and at that point you can intervene... if it's a technical question, through the nurse, or with a call to the psychiatrist, and they feel less anxious. »
>
> (professional, social worker)

In turn, these professionals with different knowledge create other relationship spaces with the users. For their part, the people undergoing treatment greatly appreciate this type of support, which is not easy to evaluate in terms of service quality, but whose value should be recognized.

In Catalonia, health services are evaluated through a survey addressed to recipients of care, in our case through the mental health services, to assess the attention they received. Known as the *Pla d'enquestes de satisfacció* (PLAENSA© the Satisfaction Survey Plan), the regional health authority, CatSalut, has run the survey since 2001 to measure service quality and levels of user satisfaction with each area of the public health service. It is available at the following link:

https://catsalut.gencat.cat/ca/coneix-catsalut/presentacio/instruments-relacio/valoracio-serveis-atencio-salut/enquestes-satisfaccio/index.html

3.3. Professionals' views on pharmacological treatment

Preparing this Guide provided the opportunity to listen to professionals' views about their involvement in and responsibility for pharmacological treatment. Their accounts reveal certain discrepancies with the system, medication itself, and their supporting role in the treatment.

Discrepancies with the care system

Limited time to attend to service users, pressure on the care system and staff shortages

The present care system imposes certain limitations on the time spent caring for people experiencing mental suffering, which can undermine the quality of the service. The professionals in the team are aware they need to devote time to getting to know the person when considering pharmacological treatment. Additionally, any possible change or modification to the dosage will require support through more frequent consultations.

How can professionals support a proposal to discontinue medication if they cannot see the person regularly? The professionals recognize that they need a strong, cohesive relationship network for their own support, and that in turn supports the person.

> « I think something that makes our work difficult is patient load; we have half an hour for each patient, which I think is enough, but because we have so many, we can't see them as frequently as we would like and I think that has a huge impact because we focus more on the question of medication because it's faster and more efficient and lets us spread out appointments. I think this is important. »
>
> (professional, psychiatrist)

The high number of people and problems that each professional has to attend to is a serious challenge. Staff shortages in care services can sometimes be a reason why medication is prescribed, which in turn can lead to situations of possible malpractice. Clinical guidance often recommends a person-centered model, but the patient load means that pharmacological treatment prevails over other more time-consuming, long-term therapeutic approaches.

Different services, different ways of working

Each service has a different purpose and way of working, which will determine the kind of intervention it carries out. For this reason, it is important not to make generalized assessments about the work professionals do, but take into account the context and specific factors of the space in which the care is given.

> « There have been changes in working methods. Flaws in the system. An intervention in the health center, when the person is able to rationalize what's happening to them and express themselves, is not the same as when they are in a crisis situation. It is more difficult to put yourself in their position in an emergency, but it's not impossible. In my experience, people work differently in different places. And yes, there is a need to review mental paradigms and increase training... »
>
> (professional, nurse)

Demand and need for supervision and continuous training

For professionals, spaces for supervision and continuous training are essential, mainly as places for support in their work and somewhere to share their unease and difficulties. This training should also follow a community approach and perspective that can be adapted to the needs raised by families and the people who use the services.

Care of professionals

Professionals also need care, which in turn helps them develop good practices in their work.

> « We work with huge levels of serious cases, anxiety and pathology, don't we? And sometimes professionals don't look after each other very well. I think this should be taken into account too... »
>
> (professional, PFP)

An indirect function of some clinical spaces may be to care for their own professionals. As mentioned above, regular, specialized supervision sessions (such as pharmacology, physiotherapy, family or institutional therapy, etc.) are spaces for talking about technical and emotional difficulties around a specific situation where people can be enabled to cope with suffering. Other proposals, such as certain work methods, can also support not only users, but also professionals. One example is the open dialogue method applied in the Badalona II AMHC and other services.

Opinions about medication

The stigma associated with medication

The professionals acknowledge that many users, and sometimes also their family members, have a low opinion of mental health medication. This can be a hindrance in practice (when recommending medicalized treatment, prescribing medication, etc.) as rejection is commonly encountered.

> « Mental health medication has a really bad press; there's the question of chronicity, although a lot of other treatments are also very harmful, but this is especially demonized. »
>
> (professional, nurse)

Medication as a mediating factor in relationships

Prescribing medication can condition the relationship between the psychiatrist and the user. The professional may experience a feeling of *loss* when interacting with the other person, a settling into the prescribing role.

> « Prescribing medication has a conditioning effect; for me, there's a certain feeling of *loss* in my relationship with the other. You settle into the role of prescribing… you ask yourself how you can go along with someone's proposal to discontinue their medication if you won't be able to see them often enough. You would need a very strong, well-connected network. »
>
> (professional, psychiatrist)

Medication as a routine

Pharmacological treatment has gained ground in professional practice, to the point that it has become the natural course of treatment in the protocol, and as a result, it often stands in the way of any critical thought or position on this course of action.

> « I think we've all fallen in with the rationale that medication is fine, it's necessary, and because it's necessary we have to prescribe it. »
>
> (professional, psychiatrist)

Overmedication

All mental health medication comes with a recommended dosage set by the manufacturer. Although some professional associations have sometimes reached a degree of consensus on these dosages, the proposed dosage must be considered in light of the wellbeing of the person taking the drug, such that they perceive an improvement in their symptoms and at the same time, maintain some control over its side effects (Desnoyers Hurley, 2007). Sometimes the prescribed dosage is excessive and can cause more discomfort than benefits, with unpleasant consequences on various levels. Similarly, continuous monitoring is needed to control the dosage to assess the person's progress.

> «I think we overmedicate today. Because professionals aren't looked after properly, there isn't enough investment in psychological treatments or social policies, and the patient load is massive, prescribing medication is the quickest solution. »
>
> (professional, PFP)

> «Yes, a lot, I think that the majority overmedicate, whether because of this medical protectionism, prescribe and that way I'm covered, and well, I've done my job and if there's an imbalance it's because they've stopped taking the medication, not because I haven't really done a good job. Yes, for a start, because if you go to the emergency department or the AMHC with certain symptoms, especially psychotic symptoms, then they'll give you drugs... there are no other options. But I think it's because of this protectionism, because in practice you see that long-term recovery is no better. I think it's the mentality, this biomedical approach and the idea of protecting oneself. »
>
> (professional, nurse)

The biomedical model

Psychosocial interventions in situations of mental suffering have been highly effective, but they are still not reaching all the population. A large number of respected studies advocate combined treatment —medication, psychotherapy and psychosocial treatment— adapted to the moment in the life of the person and their preferences (García-Herrera Pérez-Bryan, J.M. et al., 2019). The complexity of situations means that in practice, care treatment is necessarily coordinated in the team, which might offset some biomedical inertia. This trend is sometimes revealed by the professional sector itself, and materializes in the increasing medicalization of care.

> «I think it's a structural thing and it's linked to interests in the pharmaceutical industry. But there's also a biomedical mentality that is deeply entrenched and biomedicine tells us that the illness is a biological disorder and the only way to stabilize it is through medication, so I think it's a structural thing.»
>
> (professional, nurse).

Professional–service user discrepancies

User/patient noncompliance

Discord sometimes arises between the positions of professionals and users. A proposal designed to be liberating will be one in which real co-management of treatment can take place, while both parties can and do take responsibility for their rights, but also their obligations. We must not forget that on occasions, the information patients are given lacks context, and does not always adapt to individuals' actual needs.

> «I think here we have an exceptional health system; it has its shortcomings, like everything, but it also has good aspects, I don't know, there's the question of people's social awareness… here, look, we have a no-show rate in the AMHC… well, I don't know if it's very high or not but it happens. People don't show up, they don't let you know… "change my appointment", it happens all the time, so there's a lack of social awareness that this isn't free and that these no-shows are really expensive.»
>
> (professional, PFP)

3.4. Thinking about your relationship with professionals

- What sort of relationship do I have with the professionals that care for me in the mental health services?

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- Have I noticed any differences among these professionals? What are they?

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- What aspects do I most value in a mental health professional?

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- What aspects would I change in my relationship with the professionals?

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Chapter 4.
Medication

Psychiatric medication now seems to be at the core of the care or therapeutic pathways of mental health service users. Around this central point revolves a “cycle of medication” that, with its dosage adjustments, withdrawals and changing daily patterns and strategies, is constantly present in the lives of those taking the medication, in tablet form or injected, as well as those who care for or support them. The medication not only alters a symptom or eases pain; it also changes the ways people feel, think, move, and express themselves and, in general, it embodies a process translated into clinical terms as “side effects”. In practice, these often adverse side effects can be as significant as the symptoms themselves, with the result that the person organizes their personal life around the medication. Other aspects can also affect this experience, such as the person’s gender, social and family situation, cultural background and relationship with health professionals and services. The prescription and use of medication have led to criticism of many issues, some of which we highlight below:

- **Medication at the heart of the treatment.** As the United Nations Special Rapporteur pointed out in his report on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, “the field of mental health continues to be over-medicalized and the reductionist biomedical model, with support from psychiatry and the pharmaceutical industry, dominates clinical practice, policy, research agendas, medical education and investment in mental health around the world" (Pūras, 2017) (Rodríguez del Barrio et al., 2014). (See also: http://undocs.org/A/HRC/35/21)

- **The temporary nature of pharmacological treatment.** In recent years, the indefinite use of medication over time is being reconsidered. A recent study published by the Spanish Association of Neuropsychiatry (AEN; Inchauspe Aróstegui & Valverde Eizaguirre, 2017) clearly questions the possible efficacy of long-term medication, during which time the harmful effects eventually become greater than any possible benefits. In contrast, there is evidence for short-term efficacy, which supports the use of minimum dosages during the first year. The report also reviews users' responses, referring to "the high proportion of patients who abandon their treatment, due to its poor results or adverse effects" (Inchauspe Aróstegui & Valverde Eizaguirre, 2017: 12).
- **Side effects *versus* effects of the medication.** Both clinical professionals and patients find it difficult to distinguish the effects of the medication from the symptoms of the disorder, especially those known as negative symptoms of psychosis (Flore et al., 2019). There is sometimes an inadequate distinction between behaviors deriving from the side effects and those that are an effect of the disorder, which poses a problem for collaborative management and creating an appropriate therapeutic alliance.
- **Medication and its symbolic effects.** Medication can interfere in the relationships between professionals and users, and between users and their carers or family members. Medication can be discussed and negotiated (altering or lowering the dosage, etc.) but it can also be a source of power abuse and coercion (for example, changing the medication without prior consent). For most people, medication also interferes in their interactions with their surrounding environment and compromises life processes

such as relationships with partners, possible job placements or participation in activist organizations (Choudhury et al., 2015).

- **Medication with a gender perspective.** Models of femininity/masculinity and gender inequalities/violence have direct consequences in managing medication and treatment. One example of this is when women are prescribed higher doses of psychopharmaceuticals than men. Women are subjected to guidelines that frequently do not align with their biological characteristics. A gender perspective is not applied when prescribing, which may lead to possible overmedication (Valls-Llobet & Loio, 2014). Gender differences in the experiences of side effects are also relevant (see section 4.6. Mental distress from a gender perspective").
- **Medication and necessary complementary care.** The physical side effects of psychiatric medications can have serious medium- and long-term repercussions. Special care guidance is therefore needed to counteract these effects (Morrison et al., 2015).

4.1. Reflecting on the subjective experience of taking medication

> « Sure, you always feel like you've just woken up, you're slower, you don't react in the same time, people speak to you and you aren't there. You're in the conversation, but you aren't paying attention to it, you're somewhere else. You don't have hallucinations but for me the price you pay is too high. It's like living a low-calorie life. You don't have hallucinations but you don't have much else either. Many other thoughts that were actually positive. But with that medication, we could say it washes everything away. »
>
> (user, male)

» Why did I start taking psychiatric medication? (examples: I wasn’t sleeping well, I was having strange experiences, I was suffering, my doctor suggested it...)

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» Why am I taking psychiatric medication at the moment?

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- Has the medication had a satisfactory effect on the problem I had?

- What explanations have I been given about the medication I'm taking? (possible adverse effects, approximate length of the treatment...)

- If I did receive information, who gave it to me?

- Was I able to decide whether or not to take this medication? Was I given different options to choose from? (dosage, type of medication, how to take it...)

» How did my immediate circle react to the prescription? (medication guidelines I received)

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» How long have I been taking medication?

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Other questions to continue reflecting…

» At the moment, can you imagine your life without medication? YES/NO. Why?

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» Have you ever tried to stop taking the medication or reduce part of the dosage? YES/NO. Why?

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» If yes, what happened?

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4.2. The effects of medication

You have likely been taking medication for some time, so it is important to assess what effects the medication is having on you.

» What effects, both positive and negative, are the medications having?

Positive ....

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Negative

- ...on my body? (physical effects like disturbed sleep, trembling, unusually rapid heartbeat, weight gain…)

- ...on my mental state? (anguish, anxiety...)

» ...and what effects does the medication have on my relationships with other people?

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» Some people say they find it difficult to distinguish whether a negative reaction is part of the symptoms of the disorder itself, or due to the side effects. In your case...

Can you say which elements can be distinguished? How are they different from one another?

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> « Sometimes you haven't been aware of the side effects until one day, when the medication is reduced, you realize that your muscles aren't stiff anymore and you can run... and you hadn't run for 15 years...! »
>
> (user, male)

> « The adverse effects of the medication aren't just a physical thing; they are effects that everyone can see... not just me. »
>
> (user, male)

4.3. Symbolic aspects of medication: the personal and social impact of medication

Psychiatric medication can have multiple effects: desirable effects that positively incentivize treatment of the discomfort, or undesirable, negative effects. But at the same time, medication may have numerous symbolic meanings, created by the person based on their subjective, lived experiences.

» Which elements might symbolize or represent the medication for me?

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To help you answer this question, below are some words and expressions mentioned by people we have interviewed. Perhaps you identify with some of them, or perhaps they give you ideas that you associate with your own experience. Circle any that seem significant to you.

manipulation

work

housing

income

routine

healing

illness

“the price to pay”

coercion

mistrust

psychiatric hospital

control

dependence

legal drugs

insecurity

self-confidence

side effects

stiff muscles

help

“conditions your daily life”

crutch

miracle

care

experience

“being sold out”

It might help to express yourself through drawings or images that symbolize your thoughts:

In general...

- Medication and how it is experienced is always a very personal question.
- The subjective experience can depend greatly on each individual and can be experienced in different ways.
- The subjective and symbolic experience of the medication can change over time and is never static.

4.4. Knowing about medication. Important information

About the name of the medication

(Source: Col·legi de Farmacèutics de Barcelona, (Barcelona College of Pharmacists https://www.cofb.org/)

Scientific name

This is the name used by the medical and pharmaceutical community. When it is adopted by the WHO (World Health Organization), it is known as an INN (international nonproprietary name).

Trade name

This is the name given by the pharmaceutical company that markets the drug and is usually the legally registered name. The laboratory that manufactures the medication assigns the name, so a single scientific name may be marketed under various trade names. Drugs may also be marketed under the name or brand of the accredited laboratory or manufacturer. Medications that have been shown to have the same therapeutic effects are known as generics.

For example, olanzapine is the international nonproprietary name for the pharmaceutical, whereas Zyprexa is one of the trade names it is marketed under.

What is psychiatric medication?

All drugs used to treat mental suffering fall under this label, and are also known as psychopharmaceuticals. They can be classified into three major groups:

- Antidepressants
- Neuroleptics (also known as antipsychotics)
- Anxiolytics

Although their names suggest they have a specific use according to the diagnosis—antidepressives in the case of depression, antipsychotics in the case of psychosis (schizophrenia, schizoaffective disorder, various psychoses...), anxiolytics for anxiety—in practice they are often prescribed in combination to address each person's symptoms, which may be primary (related to their diagnosis) or secondary, caused by taking the drugs.

Mood stabilizers are another group of psychopharmaceuticals, most of which are anticonvulsants (valproic acid, lamotrigine, topiramate or carbamazepine) or related to GABA neurotransmitters (gabapentin, pregabalin).

Other commonly prescribed drugs are those used to treat the side effects of those mentioned above, such as antihypertensives and antiparkinsonian drugs.

This practice is known as **polypharmacy**. There is consensus that using various medications at the same time should be avoided. However, the more serious the symptomatology, the more difficult it is to adhere to **monotherapy** (using a single drug to treat the symptom). Polytherapy/polypharmacy should be avoided because it increases the side effects and interactions between the various drugs.

4.5. Knowing my medication. What am I taking?

In the forms below (standard form attached) we suggest you write down the most relevant information about each of the drugs you are taking. This may give you a better understanding of the effects they have on you and help you assess them.

The glossary at the end of the Guide provides useful explanations of any terms you may not be familiar with.

Standard form:

Name of the medicatio..

Family: ....

....

Dosage:..

....

Therapeutic effects: ....

....

Adverse effects: ....

....

Contradictions: ....

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Interactions: ....

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....

Possible effect of reducing the dosage or withdrawal: ....

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About the patient information leaflet

Every medication comes with a patient information leaflet that provides the basic information about what it is for and how it should be used. It also contains information on side effects, calculated from statistical analysis; however, the number of actual cases is not usually specified. These warnings should therefore be seen in perspective, although it is valuable information to bear in mind.

> « Yes, because the patient information leaflets that come with the drugs, I don't even look at them, I never look at them because if I read them I wouldn't take them. Because I'd read: probability "sudden death" (laughs). I don't read them and that's that. »
>
> (user, female)

The most important points they may contain are:

1. What the medication is and what it is used for.
2. Before taking the medication. Warnings.
3. Interactions. What happens if you take the medication in com bination with other medications.
4. Interferences with diagnostic tests.
5. Pregnancy and breast feeding.
6. How to use the medication.
   - What happens if you take more than you should
   - What happens if you miss a dose
7. Possible side effects.
8. How to store the medication (including the expiration date).
9. Additional information:
   - Composition
   - What the contents of the package look like
   - Marketing authorization holder and manufacturer

4.6. Mental distress from a gender perspective

Women experiencing mental health problems may encounter other gender-related aggressions throughout their lives. Their economic independence and housing options may be limited; they may bear a greater burden of stigma and face frequent disbelief about certain disorders; and they may experience gender violence as a result of their situation of vulnerability and lack of social recognition. Gender should be analyzed in conjunction with other variables such as cultural background, racialization, socio-economic level, caring responsibilities, sexual orientation, etc. Calls to include the gender perspective in mental health care in general, and in prescribing medication to women in particular, are therefore taking into account the intersectionality of conditioning factors that increase the likelihood of suffering; in other words, the simultaneous convergence of situations that can cause distress. In particular, women with a diagnosis experience higher rates of violence than other women, but also more varied types of violence. Their mental suffering means they are more vulnerable to violence and at the same time, the possibility that their suffering is caused by patriarchal violence is hidden. In other words, gender is a key variable in understanding the phenomenon of violence, but it is rarely included in clinical analyses. More generally (not only when prescribing medication), and drawing on analysis from the gender and intersectional perspectives, the first step should be to "ask the other question". In other words, when we are thinking about any phenomenon that seems obvious on the surface, we should ask whether it might not be caused by the gender variable. To do this we need to include other variables in our interpretations of what we observe.

The gender perspective in drug prescription

As a matter of course, pharmacological treatment involves the care and support of a team of professionals to monitor its effects, find the right dosage, and control for possible adverse effects and interactions with other drugs, etc. In the case of women, biological considerations, but also personal situations or circumstances should be taken into account. Prescribing from a gender perspective should be intrinsic to medical practice. Professionals have identified the following issues where a gender perspective should be applied in prescribing, and in mental health interventions in general:

- Anticipate and discuss with patients the risk that oral contraceptives can reduce the efficacy of certain drugs (importantly, women should also discuss this with their gynecologists).
- Insist on informed, written consent when prescribing certain medications to women of childbearing age, as they may affect their chances of becoming pregnant or may harm the fetus (for example, valproic acid, carbamazepine or topiramate) (Weston et al., 2016).
- Increase psychotherapy and/or psychoeducation sessions if the woman wants to become pregnant or is already pregnant, in order to avoid using medication.
- If available, use specific pregnancy monitoring programs when the woman is taking psychopharmaceuticals to intensify outpatient medical supervision.
- Develop protocols to detect and raise awareness of the gender and patriarchal violence experienced by women with a diagnosis.

  More information (in Spanish) on patriarchal violence and women with a diagnosis can be consulted at the following links:

  https://consaludmental.org/publicaciones/Investigacion-violencia-genero-salud-mental-2017.pdf

  http://asaenec.org/wp-content/uploads/2014/02/Gu%C3%ADa-de-atencion-a-mujeres-maltratadas-con-trastorno-mental-grave.pdf
- Keep in mind the different concerns men and women have about side effects. Among men, the greatest worries are erectile dysfunction, delayed ejaculation, gynecomastia, low libido, anorgasmia, muscle spasms, sleep disruption, tiredness, motor and mental slowness, and isolation. Women's concerns include excess weight, obesity, bloatedness, body appearance in general, anorgasmia, menstrual disorders including amenorrhea, galactorrhea, teratogenic effects on the fetus, alopecia, sedation,

sleepiness and tiredness. These lists give some examples for both sexes and are by no means exclusive.

It is therefore important to understand that gender is not simply a ‘women’s’ issue, but that it also has repercussions for the way professionals view masculinity in diagnosis and prescription. Likewise, family care, support from the social network and third sector professional practice are all genderized, both for women and for men. The gender variable should therefore be considered in a broad, cross-cutting sense, not only for subjects but also health institutions (the hierarchical structure of teams, types of clinical practice, how formal and informal care is hidden and/or structured hierarchically, etc.)

4.7. Prescription and diversity

Pharmacological treatment also needs to adapt to the cultural and ethnic diversity of service users. This adaptation may be referred to as intercultural competence in mental health, and is defined as the capacity of professionals and services to recognize the cultural aspects that identify service users, as well as professionals and carers. If you think there are cultural barriers that interfere with your treatment or how your disorder is understood, it is important that you tell the professionals about it. A guide to intercultural competence in mental health (in Spanish) is available at the following link:

https://www.mscbs.gob.es/profesionales/saludPublica/prevPromocion/promocion/desigualdadSalud/competencia_intercultural.htm

Chapter 5. Exercising your mental health rights

Although the rights of mental health service users and their families are enshrined in a formal legal framework, many of them continue to feel dissatisfied with or uneasy about some situations they have experienced in which they consider their rights have been violated. Ortiz Lobo (2013:262), citing David Oaks (2011), identifies "three important determinants of the systematic violation of rights in the traditional psychiatric system: physical imposition of treatment by force without consent, fraud committed by professionals who provide incomplete information about the effects of treatments, rights and alternatives, and the fear caused by a system that subjects its users to a brutal power imbalance". Current examples include removing patients' personal items on admission to hospital, administering drugs without appropriate explanations, withdrawing usual treatment on medical grounds without prior consultation with the person, isolating patients in 'holding rooms' or mechanical restraint, especially in hospital units during crisis situations.

At the same time, the opinions of people who experience mental distress are often hidden or made invisible. In this vein, Marta Allué talks of "de-moralized patients", those who by dint of "suffering an illness, or mental instability, are prevented from defending personal opinions, they are deprived of the capacity to do so, they are considered *in firmus*, morally and physically weak" (Allué, 2013:181). This idea imposes a limitation, a barrier to their credibility, that inevitably ends up placing the person in a situation of serious vulnerability and disadvantage vis-à-vis the health system (Serrano-Miguel, 2018). Partly based on this premise, the day-to-day workings of the health services have helped to naturalize certain practices that continue to attract attention and whose advisability is questionable (Leal, 2009).

For years, people affected by mental distress have been trying, unsuccessfully, to make their demands visible and have them recognized as rights. Proof of this is the United Nations Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Pūras, 2017), which recognizes three major factors that maintain the status quo in the field of mental health, namely: (a) dominance of the biomedical model, to the detriment of investment in psychosocial services and resources; (b) power asymmetries, which undermine the rights of service users to make decisions about their health and cause violence on many levels; and (c) the biased use of evidence in mental health, which limits research to biological determinants, and thus biases investment criteria. The Special Rapporteur's report calls for a paradigm shift to guarantee the right to the promotion of mental health. It states that "Reductive biomedical approaches to treatment that do not adequately address contexts and relationships can no longer be considered compliant with the right to health. While a biomedical component remains important, its dominance has become counterproductive, disempowering rights holders and reinforcing stigma and exclusion" (Pūras, 2017:19). "Coercion, medicalization and exclusion, which are vestiges of traditional psychiatric care relationships, must be replaced with a modern understanding of recovery and evidence-based services that restore dignity and return rights holders to their families and communities. People can and do recover from even the most severe mental health conditions and go on to live full and rich lives" (Pūras, 2017:21). The report ends with the following conclusions:

"The crisis in mental health should be managed not as a crisis of individual conditions, but as a crisis of social obstacles which hinders individual rights".

“[…] should prioritize policy innovation at the population level, targeting social determinants and abandon the predominant medical model that seeks to cure individuals by targeting ‘disorders’”.

“[…] Effective psychosocial interventions in the community should be scaled up and the culture of coercion, isolation and excessive medicalization abandoned” (Pūras, 2017:22).

In this chapter we invite you to reflect on your personal experiences and exercising your rights during your particular journey. Some resources and further materials are listed where you can find more information or report situations you have experienced.

5.1. Thinking about your rights

- As someone who has been through situations of mental distress, have you ever experienced a situation in which you consider your rights have been violated? If so, can you describe what happened?

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- Do I know my rights as a mental health service user?

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- Do I exercise my rights? How?

- Where did I receive information about my rights, and who gave me it?

- If I want to obtain information or find out more, do I know where to go? Could I name a specific place to go that is relevant to me?

- Do I know my rights regarding pharmacological treatment?

» Can I refuse to take a treatment?

» If any of these rights have been violated, do I know where to go and what to do?

- And if I wanted to make a formal complaint, do I know what to do and where to do it?

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5.2. Violation of and compliance with medication rights

During the preparation of this Guide, we heard from people who feel their rights have been violated. In this section we include some narratives that can help us reflect on possible violations of rights related to psychopharmacological treatment. We refer to Articles from Spanish *Law 41/2002, of 14 November, regulating patient autonomy and rights and obligations of information and clinical documentation (Ley básica reguladora de la autonomía del paciente y de derechos y obligaciones en materia de información y documentación clínica*), which should be interpreted as compliance with the United Nations Convention on the Rights of Persons with Disabilities (2006) ratified by the Spanish state:

Entitlement to be informed of your rights during a hospital admission and the right to receive healthcare information about all interventions that affect a person's health (which includes the right to receive verbal information on the purpose and nature of each intervention, the risks and consequences, and the prescription of medication and its side effects, contraindications, etc.) (Art. 4)

« Now I get the feeling that they don't tell you much, at least in my case, I don't know about the others. I don't have much information about the others. In my case, when I was admitted to San Rafael it was voluntary, there they started only admitting through the emergency department and I said, 'look, I'm taking these tablets.' I was taking treatment prescribed by another doctor, though I'd stopped going to appointments five years before, but I still kept on taking them. I said that I had to take them and when I went in they told me to 'calm down' and they gave me a tablet, it was yellow, I remember, and sweet. They don't tell you that they take away all your medication and you only find out when they've taken it. Then they suddenly give you something, but you don't know either what they're giving you or what they aren't giving you. They give you it before you eat, they come round with a trolley and they call your name and you take it, in the dining room. You see the doctor but you find out they've prescribed medication because they give you it at mealtimes. That's what happens. There I think they should tell you, 'so you're going to take this because we've found that you've got this…' they gave me my diagnosis when I'd already been there three weeks taking medication. And as for the rest, sure we have rights and there's all that business of advance directives, things we don't know about, that we aren't aware of and perhaps they'd be good for us in many cases. I don't know if I'd want to use it but if they exist there'll be a reason for it. Everyone should know more about it. »

(user, female)

After reading this account, we ask you to think about the following questions...

- Have you ever been in a similar situation? Do you remember what happened?

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- How did you resolve the situation?

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» Would you change anything now about the position you took then?

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The right to receive necessary, true information in a form that can be understood and is that is appropriate to your needs (Art. 4)

« Informant: They should get to the point when they're speaking, because they sometimes talk about medication and they ramble on and on. And, like, sometimes they don't realize that the person they're talking to, well, they don't get more than half of what they're saying, or they half understand it. Because, sure, they might be talking about the side effects, the effects of a drug, and, naturally, the person the doctor's talking to, they're interested in the side effects, not the effects the medication has, but, I don't know how to explain it…

Interviewer: You're explaining clearly… you mean, that the person's interested in the side effects and psychiatrist isn't?

Informant: No, that the psychiatrist talks a bit about the medication, the effects it has on the illness, maybe, that's what I didn’t make clear, and that the person’s thinking about the side effects, and then of course one thing isn’t compatible with the other maybe, and that’s why the patient doesn’t want to take the medication afterwards. And that’s essential. »

(user, female).

« Patients have the right to be informed, but to be really informed. When you go to hospital and they give you an informed consent [form], they don’t actually explain the complications a treatment might have, and you sign, passively, and that’s that… then the complications come and it’s like, nobody told me. Well, we do the same thing here… the truth is that we don’t give much information about the complications, so it’s important for the person to get involved too and ask for it. »

(professional, psychiatrist)

» Based on your experiences, do you think people are properly informed about the treatment they are going to receive?

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» And is the information easy to understand? YES/NO

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» Where do you look for information to answer any questions you might have?

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Rights related to treatment: "right to free and informed consent", including the right to refuse the proposed treatment, within the legally established limits (Arts. 8 and 9)

> « What I like [about a named professional] is that they start with your rights. And when you go to a doctor, they don't mention your rights, it's just "take this and that's all". »
>
> (user, male).

> « I know of cases where people have been given ECT without being asked, right?… they consulted the family, and it isn't the family that should decide about your wellbeing. »
>
> (user, male).

> « I don't think they think about it in terms of rights, they aren't so militant, but they do often try to negotiate. Often, right from the start, there are people who'll say, "I don't want anything that makes me sleepy or put on weight", but they do negotiate, even though they don't specifically see it as such, but they are negotiating and well, I do consider it as a person's right to negotiate and say no, they are adults. I don't like working with minors because they can't decide. But these people, yes, if they are adults they have the right to say no. »
>
> (professional, psychiatrist)

- Have you any experience of similar situations?

- Do you think service users and professionals negotiate treatment in mental health consultations? Why?

Other situations to think about with regard to rights...

- On being accompanied or not in medical consultations: the "right to be accompanied or to be alone in a consultation" is not recognized as such, but it is covered under the "right to privacy" (Art.7 Law 41/2002), which is a fundamental right protected under the (Spanish) constitution (Art. 18). Information about a person's health always belongs to the patient, so only they can decide who to share it with.
- The right to refuse a given pharmacological treatment and to continue consultations or follow-up with health professionals. The right to health protection is recognized in the Spanish constitution (Art. 43).
- The need to negotiate or promote shared decision making. The right to informed consent and observance of its limits (Arts. 8 and 9 Law 41/2002).
- The right to freely decide matters of health care and treatment in advance. The right to issue previous instructions (Art.11 Law 41/2002).

5.3. Exercising your rights

Possible questions to ask about your medication

Any doubts you might have about your medications should be resolved by the health professional who prescribed them. Thinking about the list of questions below and answering them with the health professional may help you to exercise your rights as a patient/service user and anticipate any possible violation of your rights.

- Why do I have this indication?
- What are the beneficial effects?
- What are the side effects?
- Are there any contraindications?

- Can I take this medication with the other ones I'm already taking?
- When should I take this medication? Do I have to follow any particular guidelines? (e.g. after meals)
- Is there any alternative? If so, what?
- Should I have a medical examination before I start taking it and then be monitored while I'm taking it?
- Is there a maximum daily dose?
- What are the risks in the case of an overdose?
- Is there any difference in the dosage for men and for women?
- How long will the treatment last?

Where to register a complaint or report a situation where your rights have been violated

- **The mental health service where you received attention**

  Mental health services or facilities are legally obliged to have appropriate mechanisms to deal with patients' complaints or grievances. Ask for the name of the person who can tell you how to go about this.

- **Patient support service/office**

  Public health services such as hospitals have patient advice and support services.

- **Catalan Ombudsman**

  The Ombudsman's role is to deal with complaints from the population against actions, or failure to act, by the public authorities. He or she oversees the proper working of public authorities at all levels by supervising and collaborating with the Catalan administration. He or she also oversees private companies that supply public services. The Ombudsman is politically independent, is not attached to any government, and acts objectively, independently and under his or her own criteria.

https://www.sindic.cat/en/page.asp?id=27

The Ombudsman has a department devoted exclusively to guaranteeing the rights of patients and health service users: the patient advocate (defensor del paciente).

http://www.sindic.cat/es/page.asp

- **Office for Non-Discrimination (OND)**

  Since 1998, Barcelona has had its own city council service, the **Office for Non-Discrimination**, to deal with human rights violations in all areas of discrimination. The OND provides information, training and awareness raising in equal rights, and offers care and advice to victims of human rights violations.

  https://www.coe.int/en/web/interculturalcities/-/office-for-non-discrimination-ond-#:~:text=The%20OND%20is%20a%20mechanism,sexual%20orientation%20and%20gender%20identity.

- **Observatori de Drets en Salut Mental (Mental Health Rights Observatory)**

  This is a critical, dynamic space devoted to monitoring policies and regulations that specifically affect the rights of people with a psychiatric diagnosis and their environment. The Observatori de Drets en salut mental is an initiative of the Federació Veus de Cataluña.

  https://veus.cat/qui_som/

Space for consultation: bioethics committees

A healthcare ethics committee is an interdisciplinary, consultative body designed to help health center professionals and users. They analyze and advise in the resolution of ethical conflicts that may arise in healthcare practice, and their aim is to improve the ethical dimension of clinical practice and the quality of healthcare.

Although they can answer questions, they do not offer legal advice and their decisions are not binding.

5.4. Basic mental health regulations and legislation

Basic legislation

- United Nations Convention on the Rights of Persons with Disabilities, 2006.

  https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

  http://www.un.org/spanish/disabilities/default.asp?id=497
- Spanish Constitution, 1978, Art.18, on the right to privacy; Art. 43, on the right to health; and Art.49, on the specific prevention and specialized attention to people with a disability.
- Law 14/1986, 25 April, on general health.
- Law 41/2002, 14 November, regulating patient autonomy and rights and obligations in matters of information and medical records.
- Law 21/2000, 29 December, on the rights to information on health and patient autonomy, and current medical records.
- United Nations Human Rights Council Resolution “Promotion and protection of all human, civil, political, economic, social and cultural rights, including the right to development: mental health and human rights”, September 2017.

- Pūras, D. (2017). Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.

  http://undocs.org/A/HRC/35/21

- Charter of citizens' rights and obligations in matters of health and healthcare.

  https://catsalut.gencat.cat/ca/coneix-catsalut/acces-sistema-salut/reclamacions-i-suggeriments

Publications (in Spanish and Catalan) on rights by civil society groups, activists and professionals

- Guía de drets de la Federació Veus.

  https://veus.cat/es/derechos/

- Informe Alternativo ActivaMent-Hierbabuena sobre la situación de los DDHH de las personas con discapacidad psicosocial en España (2019).

  https://activament.org/es/2019/activament-i-hierbabuena-presenten-un-informe-davant-lonu-sobre-la-situacio-dels-ddhh-de-les-persones-amb-discapacitat-psicosocial-a-espanya/

- Documento de voluntades anticipadas y la planificación de decisiones anticipadas. Comitè de Bioètica de Catalunya (2018).

  http://canalsalut.gencat.cat/ca/detalls/noticia/respecte_voluntat_persona_trastorn_mental

- Informe sobre el estado de los derechos humanos de las personas con problemas de salud mental en España de la Confederación Salud Mental España (2018).

  https://consaludmental.org/centro-documentacion/derechos-humanos-discapacidad-2018-46460/

- Manifiesto en torno a la coerción en los servicios de salud mental. AEN (2016).

  https://aen.es/manifiesto-en-torno-a-la-coercion-en-los-servicios-de-salud-mental/

- Derechos humanos y hospitalización psiquiátrica. Por una ética de la capacidad. La vida diagnosticada. Fundació Congrés Català de Salut Mental. FCCSM (2016).

  http://www.fccsm.net/portfolio/derechos-humanos-y-hospitalizacion-psiquiatrica/

- Documento de planificación anticipada de decisiones en salud mental. Guía de apoyo para profesionales y personas usuarias de los servicios de salud mental de la Escuela Andaluza de Salud Pública (2015).

- Derechos Humanos, Ética y Salud Mental (I). Tratamiento Ambulatorio Obligatorio. Medidas Restrictivas. Fundació Congrés Català de Salut Mental. FCCSM (2005).

Chapter 6. Conditions for dialogue

For most people, an experience of serious mental suffering, such as a psychotic episode, disconnects them from their social world. This situation may be aggravated by certain professional interventions that in themselves constitute an exercise of power and that in some cases may violate the most basic human rights (Beviá & Bono del Trigo, 2017). Providing a ‘safe space’ where people can talk about their suffering and symptoms, without the risk of being forcefully admitted to hospital or other coercive interventions, can encourage or rebuild bridges for communication between everyone involved, including professionals. Several studies have shown how approaches that ignore communication and good social relationships only contribute to a worsening or stagnation of the patient’s situation. Authors such as Jaakko Seikkula, referring to the Finnish Open Dialogue model (Seikkula & Arnnkil, 2016), place the issue of communication at the heart of their work. A possible breakdown or deterioration in communication contributes to the worsening of the person’s symptomatology, which can be even further aggravated when strategies such as hypermedication or isolation are applied following admission in situations of suffering. These authors also report notable improvements in patients when the contextual conditions allow these channels of communication to be developed in a stable, safe way (Seikkula et al., 2016).

The narratives of the people involved in the CMM project include demands related to communication. The accounts from interviews and focus and discussion groups form the basis for some proposals, outlined below, to strengthen dialogue and communication among the actors involved (Serrano-Miguel & Martínez-Hernáez, 2020) (in press) “Apuntes para el diálogo en salud mental “. *Revista Polis e Psique*.

6.1. Initial conditions

Information

From the beginning, the narratives highlighted the need for people to have enough information to enable them to try to understand what is happening to them and the treatment they are receiving.

> « Being lucky means getting a professional who empathizes with your situation, who listens to you, who supports you, who explains things that, especially at the beginning, you know nothing about… Who is there with you when you hit the ground. Who explains what you’re going to find. Who understands that for the professional everything is new too. The thing about mental health, if you haven’t had anyone in your family, it’s a blow … you don’t understand anything. »
>
> (user, male)

According to the users, information should be “sufficiently understandable” and must avoid stereotypes. The side effects of neuroleptics and overmedication must also be taken into account in preparing a space for communication, as they limit the patient’s ability to express themselves and their possibilities for negotiating in the clinical and domestic setting. As long as it respects the person’s right to privacy, in some way the information “should be addressed to all parties”, should avoid any hint of unidirectionality, and should not create knowledge hierarchies that raise barriers to the exchange of information about treatments, care, and the experience of suffering.

A suitable pleasant space

The informants also called for somewhere specifically designed for dialogue, physically “a pleasant, well looked after place where you can have something to drink when you come in”; and symbolically, understood as a “safe space”, a place “where I’m welcomed, not rejected”, a place where uncertainty is supported (Seikkula, 2016) and that encourages people to express their emotions; a place that “respects previous attachments, spaces of trust, and decisions taken”.

6.2. Building relationships based on dialogue

> « Yes, I’ve been lucky I think, I found a human person… it’s just that some doctors don’t… they might be brilliant but they’re cold… they don’t make contact with you. Me, well I came out of the clinic better than I went in, you know? […] when it’s been a long time, of course… they have to do a summary… I’d say, let’s see, what shall I tell you? but then I’d go away happier because they joked with me, I don’t know, they gave me hope… I could see that they liked me. »
>
> (user, female)

People who suffer with their mental health greatly appreciate the relationship they have with the professional. Their interest or willingness to talk about what is worrying them will depend on this relationship, as this user notes:

> « When there’s a basis of trust there can be a few confidences. »
>
> (user, female)

This connection comes with a “good manner” (Leal, 2006) as the basis for any “good treatment”, something that one of our informants expressed in their wish that “a filter of humanity could be applied to psychiatry”.

A relationship ideally based on:

Empathy and honesty

> « ...well, I think there has to be an empathetic relationship in which the psychiatrist is also honest with himself, plainly and simply. »
>
> (user, male)

Affection

> « I look for affection and understanding in the professionals. »
>
> (user, male)

> « Often people reject a doctor because you leave the consultation worse than when you went in... »
>
> (user, male)

Connections maintained over time

The relationship should also have some guarantee of continuity, without arbitrary changes that tend to lead to “situations that, while not hostile manifestations, can be experienced as insufficiently appropriate” (Leal, 2009: 167).

> « Changing from one psychiatrist to another is a problem, and it’s happening a lot recently and it’s a problem, changes have an effect. And I don’t know if we handle these changes carefully enough because it happens, people take leave, someone retires, another person has a long period off work... there are always changes, and the patients tend to make comparisons. »
>
> (professional, psychologist)

Trust

In the development of this relationship space it is particularly important to gradually build a connection of trust, through which the person feels they can express themselves and speak without worrying that they may be subject to any type of coercion.

> « You see that someone wants you to take medication, to calm you down, with every good intention… but that makes you distrustful. »
>
> (user, male)

Loss of trust may coincide with certain rifts and is usually the result of a unilateral approach, or of a limited or indeed no appropriate space for the encounter where, for example, the person affected can choose who they want to be involved in their therapy.

This set of circumstances eventually silences certain narratives. On the reasons why someone may not speak in a consultation, one informant explained:

> « Sometimes because of a lack of trust, I feel scared because I've been through a lot. Sometimes we speak and they put words into our mouths. Sometimes I've felt that others read my thoughts and I don't know if that's easy. Although it's always good to exchange information. »
>
> (user, male)

Horizontality

Establishing a relationship based on dialogue can be useful to disarm a certain principle of authority that pharmacological treatment seems to covertly impose and at times, is manifest in threats of hospitalization, or the loss of financial resources or social housing:

> « For example, I don't take my midday tablet. Yes, I admit it, sometimes for long periods of time. But I always take the rest of my medication because the psychiatric hospital fills me with panic. Why would I go clean? To end up in hospital in a year's time? No, I'm not going back there. They screwed me over once, but they won't do it twice. They really shafted me in X Service, that's why I say I'll never go back into the psychiatric hospital. Aye! I'd rather take the medication than go back into the psychiatric hospital. »
>
> (user, male)

However, the narratives also revealed practices and models that attempted to reverse coercive rationales. During one of the working groups in the research, a young informant explained how he and his psychiatrist had managed to enter into dialogue:

> « I talk a lot about literature with my psychiatrist. Actually, both of us know what we are talking about, but this way it doesn't feel so aggressive, and then at a certain point he asks me how I see myself… then I know that he wants to talk about how I'm feeling… if I go to the psychiatrist and I only talk about symptoms, I don't feel like a person, but in the end I only feel the hierarchies, the fears, and I'm grateful to talk about other things. »
>
> (user, male)

Using other languages

> « It's important to use language that all of us are comfortable with. »
>
> (user, male)

6.3. Dialogic practices

Rethinking and challenging (dis)functional logics

One of the most obvious aspects to emerge is the patient load felt by many professionals. This pressure imposes a pace of work and consultation frequency that prevent them from providing direct care in the time they consider sufficient. This situation gradually leads to a work dynamic based on a dysfunctional system that healthcare teams come up against on a daily basis and in which they are in a constant state of tension:

> « I think something that makes our work difficult is the patient load; we have half an hour for each patient, which I think is enough, but because we have so many, we can't see them as frequently as we would like and I think that has a huge impact because we focus more on the question of medication because it's faster and more efficient and lets us spread out appointments. I think this is important. »
>
> (professional, psychiatrist)

The uncertainty of the time available for consultations also adds instability to the relationships. Excessive bureaucracy and the lack of spaces and time force teams to rely on mechanical practices as a 'survival' strategy, the spaces created for attending to patients tend to be segmented and, most importantly, they stand in the way of building a relationship based on connection and a 'pleasant manner'. Without the time or space necessary for health professionals to listen attentively to narratives of suffering, the therapeutic process is compromised and the often defensive use of protocol takes over. Some family members highlight the instability of these relationships:

> « I think there is too much protocol in the AMHCs. For reasons of autonomy, I stayed in the waiting room. They never asked me what had happened in those three months. Despite my son saying that I could go in. Why didn't the professional ask me? »
>
> (family member, mother)

The carers express a desire to participate in at least some of the spaces where their family members are being treated. In response to this demand, however, mental health service protocol tends to defend individual rights, often alleging that they are protecting the service user's supposed will to manage their clinical space and falling back on questions of patient autonomy.

However, the right of the patient does not necessarily have to conflict with their family members' participation, which is often something they want and ask for. What is needed are organized, planned spaces where attention can be given to all parties, and which avoids this "circle of overlapping distrust," in which those involved often end up trapped.

Working collectively

The invitation to work collectively is based on integrating everyone involved into the care process, together with knowledge from all sides (including that of users), on the understanding that each person has their own value and potential for change. This involves thinking about the possibility of a cross-cutting work culture, in the broadest sense, a space where different actors are involved and at the same time, a supportive network of trust can be built up around the person; an inclusive network that does not isolate, but is a space for mutual care that supports those affected and their main carers. It looks for ways of "decentralizing" the prominent role of the family, without distancing them in any way, but integrating other people into the dialogue space, people who are significant to those affected and who can create a community of mutual care. On this point, one professional reflects on day-to-day practice as follows:

> « Maybe we should leave the door open so a trusted person can come in, perhaps not just family, make this intervention much more open. »
>
> (professional, psychiatrist)

Some association networks or first-person initiatives embody this notion of collective care and 'safe spaces' where people can express themselves. Some patients mention that their lives have changed radically since they formed relationships with these groups, because they are spaces where people can start to talk about what is happening to them without feeling questioned or judged:

> « Trust is complex; right now I wouldn't trust my family, they don't have the perspective I have and they suffer a lot. In trying to help me, my mother is capable of calling the psychiatrist and getting me on medication. The essential thing there is having someone who knows my symptoms or who understands that something isn't working. I'm in the XX Association where they know me well; for example when I don't stop walking, in my case it's a warning sign. My family loves me deeply, but I think that by trying to help, they would end up doing something that I don't want »
>
> (user, male)

It is important to recognize and encourage the care function of informal networks. (Re)connecting with the social world should be central to the treatment process if what it aims to do is move toward a better state of being. This implies introducing collective care into professional healthcare practice.

Most of the professionals defend the teamwork carried out in their work spaces. It would be interesting to consider a team action interlinked with significant individuals in the lives of the person suffering from mental health problems and thus encourage a form of "shared expertise" (Seikkula, 2016:39). The professionals involved in this network would not necessarily always have to be the professional assigned by protocol, but the most significant person for the affected individual.

Democratizing health

Attention and care for people in a situation of mental suffering are generally marked by a framework of multiple hierarchies that, in one way or another, are eventually projected onto the person and limit their autonomy. The hierarchies established with and within the team of professionals, and those that emerge in the day-to-day routine of the home all represent hurdles that the affected person has to struggle with to make a space for their voice and their decisions, and where they can express their discomfort or distress.

Most professionals seem to be used to working in a hierarchical structure in which each profession has its own defined competences and responsibilities based on the bureaucratic compartmentalization of knowledge and power (Martínez-Hernáez, 2008). In this context, psychiatrists, as those ultimately responsible for the prescription, see their professional activity as compromised. "You get used to prescribing", said a psychiatrist in one of the focus groups, accepting that this prerogative entails some kind of *loss* in the interaction with the patient since the imperative to medicate had already pervaded the relationship space.

In contrast, the spaces for caring, talking or dialogue enjoyed by other professional profiles (nursing, psychology and social work, among others) appear to be more resilient, although they are not recognized to the same extent, nor do they have as much decision-making power. In addition, the families seem to have adopted positions of knowledge derived from the responsibilities the professionals delegate to them. Their knowledge is therefore rooted in the rationale of the health system, and not so much in their recognition of the narratives of those affected (Correa-Urquiza, 2018). Often responsible for ensuring adherence to the treatment, families frequently end up exercising a symbolic power in which they eventually have a coercive, controlling function that triggers intense imbalances in the relationships. These coercive logics can only be deactivated by negotiating treatments within a horizontal relationship that fosters the autonomy of those affected and a therapeutic alliance among everyone involved.

Chapter 7. Autonomy and negotiation

In this final chapter on the subject of negotiation, we develop and suggest some strategies that people taking psychopharmaceuticals can apply to make decisions about pharmacological treatment, possible changes and/or withdrawal, and in general, to improve their ability to negotiate these issues.

The CMM Guide proposal aims to help people to build their capacity to view their treatment and the circumstances in which it is given through a critical lens. It also aims to boost participants' autonomy by rethinking this issue not so much as an individual goal, but as "being in the network" (Silveira & Cabral, 2019), thinking about and resolving situations collectively, and bringing the person's significant network into the process of dealing with their mental health problems. There is, therefore, an urgent need to open up these care spaces to the significant others who give care in order to create a network that can support the person in case of distress, an anchor that they can hold onto when they need it.

The experience of the people who have collaborated in preparing this guide clearly shows the importance of co-responsibility in the processes of modifying or discontinuing medication. Any change to the medication (whether proposed by a health professional or the person taking the drug) must occur through a process of extensive dialogue, in which the person can give a warning sign for immediate intervention.

7.1. Making decisions critically

- Show an interest, be keen to find out.
- Ask ourselves about the reality of our experience.
- Look for information from a range of sources to inform our own opinions.
- Check that information sources are independent. Information on websites is often aligned with the interests of their financial backers. It is therefore important to know which organization is behind it, its history and where its funding comes from.
- Start by knowing our rights.
- Always analyze and evaluate the pros and cons of the decision we are taking.
- Carefully study all the new information that we might see about medications and new treatments.
- Start by asking simple questions: what, who, when, where and why.
- Be open and critical: we can change our opinions at any time and we can also ask whether a solution that worked in the past is still the right one now.
- If possible, find a public body where you can explain what you are thinking.
- Feel equal to other people. Recognize your own knowledge.

7.2. Managing medication: continuing, modifying or reducing medication

In practice, there may be numerous and varied reasons to consider making changes to your medication: to see if a new product improves the symptoms, to change the way it is taken (orally instead of an injection, or vice versa) because of the discomfort it causes, to reduce the dosage partially or stop taking it all together, or simply to feel you have more control over it. At the same time, some people feel their medication is extremely important and despite the possible harmful side effects, it has improved their lives to such an extent that they do not want to consider changing it in any way:

»I thought I was taking a lot of medication«

> « In my case, since 2011, I started with the doctor I am with now in the Mutua, a couple of years ago we started to reduce it because I also mentioned that I thought I was taking a lot and he thought I was fairly stable. Then when I tell him, "look, I went through a bad patch for a while, but then I got better, didn't I? So now I'm okay and that's that". "No, no", he says, "this time we won't reduce anything, next time". So the next time, if I'm completely okay, then we reduce it a little. He has to be really sure, he's very careful. »
>
> (user, female)

»It's never worked for me«

> « It's like, in my records there are so many medications, they've never worked for me. Not one, because I… when I arrived some time ago… they stopped having any effect on me. Either they stop having any effect or they are counterproductive, or like… I have another relapse, or I get ill again. They have never, ever found the right medication. I've taken everything, all sorts: antipsychotics, antidepressants, anticonvulsants, anti… anti everything. It's like… So, the medication, really for a while I say: "ah, look… Now I feel fine. I'm feeling great! So the medication is working". But you get to the point where you lose faith in the medication, because then the changes in medication… Because sure, like I have a relapse or I'm ill again, they have to change my medication and the changes to your medication are horrible…

It’s just, they’re horrible. Like, a change in medication you go through a transition there… which is, like… nobody knows how much you suffer, what you might be going through, the withdrawal syndrome for what you’re giving up, the change to the other, how awful it can be. Then there are medications that have made me feel dreadful. Like, maybe I hadn’t had an episode and then I had one. Or, it’s just… I’ve taken everything. And I’ve never taken the same medication. I haven’t had a tablet that I’ve taken for ten years without a break, never. »

(user, female)

»I don’t want to take it, but I do as I’m told«

« The family? Well, I don’t know, they might be very interested. Or they might not be interested, I don’t know. My family for example… it’s always: “I have to take it, I have to take it”. I in… I’ve stopped taking it and I’ve had several relapses and in the end I had to be admitted. And well, now I take it but I don’t want to… it’s like, I don’t want to take it. But I do as I’m told. And this is why, because they leave me flat. Apart from that, sexually I’m incapacitated. And well, thanks to the fact I don’t have a partner, I live alone, but… I don’t know, it has affected me… »

(user, male)

»Enough so I feel stable«

« At the beginning I was taking a really brutal medication that totally wiped me out, then I had some changes to the medication and recently I was taking one medication and I thought, look, I’m going to reduce the medication bit by bit and I got to the point when I said, I’ll give it up!, eh, unilaterally, with no consensus, unilaterally, take that! [laughter] eh, I did it, like that, but I realized that I had to take the medication, I realized by myself eh, by myself and because of the people I had round me, my partner especially, she said, “you’re very speedy, whatever, try to control it more” and I realized that using the medication for my own benefit wasn’t to take it like the psychiatrist told me to, but to reduce the dosage quite a bit more, half of what they prescribed me. I take half what I’m prescribed, but that does enough good for me to feel stable and not feel… what’s the word… shit, I can’t think of the word. So I don’t feel coerced, no?, manipulated by the medication, so the right word would be manipulated. It’d be, yes, eh… Well, it doesn’t matter, manipulated is okay, you can understand it perfectly, can’t you? »

(user, male)

»I think I’m capable of experimenting«

« …I’m very experimental and very… it’s like I think I’m capable of experimenting, of skipping [a dose] and doing it more quickly and doing a two-week experiment, changing, like, for example instead of taking one tablet, take half and perhaps… I’d say that when I’ve done it, it’s because I was a bit high […] I understand that it’s wrong of me to do it, you should do things properly… if you’ve got a team behind you well, you shouldn’t do things on your own. I understand that if they give me a row they’ve got every right to. »

(user, male)

»I don’t want to touch it«

« …hitting on the right treatment, finding the tablets, the active ingredient… and well, getting the dosage right is hard… it’s taken me years. And I don’t want to touch it. For the moment I don’t want to touch it at all, I’d rather keep having the dry mouth, I’d rather keep having the trembling, so… the side effects are the price you have to pay but well, it’s worth it for me now. »

(user, male)

«I don’t want to leave them in a mess»

> « I’ve often thought about it but if I do something and I get worse, I think I’d jeopardize my children’s lives. I don’t want to leave them in a mess. If I was on my own, I could do it. »
>
> (user, male)

7.3. Aspects to consider before making changes to your medication

Possible dangers of making sudden changes to medication

Withdrawing medication suddenly without professional supervision can give rise to serious complications and even hospitalization. Taking a regular dosage of psychiatric medication leads to dependency and any reduction to the dosage must be done gradually and under supervision to avoid harmful effects to the central nervous system.

Issues to consider...

By the person taking the medication:

- Know exactly what is involved in the process you are about to start.
- Organize an action plan: identify the person or people who will help you, prepare your negotiation with the doctor or psychiatrist, draw up a schedule, know your rights, know the possible effects of reducing or stopping the medication, think about and evaluate different scenarios, arrange and organize a pleasant environment, avoid potential sources of stress. We

recommend waiting until you have enough support and a well organized network before making any changes, otherwise the risks to your welfare may be considerable.

About the medications you are taking:

- What type of medication it is.
- The dosage and its effect.
- The duration of each dose.
- Other medications taken (possible interactions or reactions).
- Other substances (natural products, vitamins…).

Possible support from your circle:

- Clarify possible help from health professionals.
- Specify what help each of these health professionals can give you.
- Arrange a support network: clarify who is included, how much time each person can offer, whether these people are connected in any way, whether they can communicate with each other easily, whether they have a comfortable space where you can be…
- Arrange to have an environment with the right characteristics for easing the change (quiet surroundings, free from stress…)

Disadvantages of making changes to medication. Possible risks

As we stated at the beginning, some people have negative experiences when they reduce their medication because of the risks of withdrawal:

Risk of relapse if medication is withdrawn/reduced without supervision

« Well, if someone feels well and they're getting better they could look at the medication, I think that stopping it all together would be a mistake. Because their illness might come back stronger, more seriously. Sure, after a long time I don't know. No? But at the start in the short term I don't think it's a good idea. I've heard of cases that, even if they go it alone, they've said: "I feel fine, I'll stop taking everything." And then they've had another relapse but they've relapsed really badly. »

(user, male)

Fear of the risk of losing resources

« Me, for example, if I wasn't dependent on the sheltered flat and I lived alone, I'd try natural medicine, whether it worked or not, but I'd be free [to try it], but as I'm in the day center, I'm really scared that they would tell me I have to go into the psychiatric hospital if I don't take my medication. I don't tell the day center referrer how I'm feeling. I've been in two psychiatric hospitals and I've been three times and I don't want to go again, I had such a bad time that I shut up about it. When I feel nervous I do coloring. »

(user, female)

Lack of information/Uncertainty

« I think so, I don't think there's enough information. More resources would be needed to tell us about all the dangers, both from self-medicating because you might get addicted to a substance, and from the complete opposite, from stopping taking some medication that you think isn't important and then getting ill. There are some people I met in hospital who think that nothing happens if you stop taking the tablets, or that they would be fine and nothing would happen if they took less. I also used to think the day would come when I'd be fine without taking anything, but now I think that if they don't make me feel really bad, I prefer to take them and stay stable rather than have another relapse. »

(user, male)

« We don't know what will happen if we stop the medication, actually nobody knows, we never know. But we can know the possible risks. »

(user, male)

7.4. Negotiating with your psychiatrist

« Well I'm very idealistic and very utopian, I'd like to think that the patient and the doctor should be able to talk about absolutely everything, what the medication and the illness involve. »

(user, male)

« Over time you distinguish between who's seeing a person and who's seeing an ill person. »

(user, male)

Preparing for the meeting

- You can draw on the issues covered in this Guide. If you like, start with the information provided here and the points for reflection we propose.
- It may be useful to write down your thoughts about why you want to make changes to your medication and take notes with you.
- Write down the beneficial effects, but also the harmful side

effects of the medication.

- Think about the improvements you may have experienced and made to your personal and social life in recent months/years.
- Be clear about the resources available to you: personal relationships, professional support, materials, etc.
- Be clear about your rights as a patient or user of a health facility or mental health service.
- Find out about situations other people have been through and have a clear idea of both positive and negative experiences. They may help to form your arguments.

Putting your case to the professional

- Put forward your proposal for changing your medication with reasons why you want to make the change.
- Listen to the answers and ask about everything you don’t fully understand.
- If it makes you feel more secure, go to the meeting with someone you trust.
- Ask the professional to support you through the process and to be there to help you and your social network.

What to do if your proposal is rejected

- It is important to clarify why the health professional reacted negatively. Perhaps they have experience of other cases, or have information you are unaware of.
- One possible option is to arrange for the professional to meet one or more of the people in your trusted circle. This may reassure them and show them that you have the support you need to manage a possible change in your medication.

7.5. Autonomy. Managing your relationship network

Thinking about negotiating pharmacological treatment and modifying medication may sometimes involve varying degrees of distress, situations of both physical and emotional ups and downs that require the particularly delicate approach and caring company of your closest circle. To cope during these times, it is important to first organize a support network that includes people closest to you as well as professionals you trust and who you can turn to.

We suggest you now decide who to include in this network and organize it around the care you want to receive if you need it, and that you think about the necessary conditions for setting up this *Care Agreement*.

> « Company over control. Lots of people disappear during an episode, but not my family. What they do, though, is normalize the possibility that I may feel ill. If things go badly, that person will be there for me. »
>
> (user, male)

Drawing up your own Care Agreement

1. Starting point: agreement with myself

- Objective(s) I have set myself regarding the medication and my treatment in general:

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- Why do I want to make this change?

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- Limits I set myself (how far do I want to go and what I’m not willing to do)

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2. Organize my support network

- If you feel ill or you need someone to help you, there may be a specific person (or more than one) who you prefer to notify or have near you.
  Write the name of that person here and the place (which may or may not be a health center) you would prefer to go to, along with other important contact information:

- We also suggest you write down any important information that might improve the organization of the care network if you need it.

Person/people in my support network

Full name

Contact telephone number

Connection (personal or professional)

Meetling place

Full name

……………………………………………………………………………………………

……………………………………………………………………

Contact telephone number

……………………………………………………………………………………………

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Connection (personal or professional)

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……………………………………………………………………

Meetling place

……………………………………………………………………………………………

……………………………………………………………………

Full name

……………………………………………………………………………………………

……………………………………………………………………

Contact telephone number

……………………………………………………………………………………………

……………………………………………………………………

Connection (personal or professional)

……………………………………………………………………………………………

……………………………………………………………………

Meetling place

……………………………………………………………………………………………

……………………………………………………………………

Times of the day or periods in the week when they are available

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Connections between these people

If there is a connection:

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If they have no connection, could they contact each other through a contact telephone number, a place they have in common, etc?

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Do they have an appropriate comfortable space to be in? Where?

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3. Support from professionals

- Clarify what possible help you can expect from the health **professionals** you would like to support you. There may be one, or several. Specify the help each one of these professionals can give you, whether or not they belong to a specific mental health service (for example, a private care network, an activist or association network, etc.)

Professional 1

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Professional 2

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....

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Professional 3

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4. Arranging a suitable space or environment

- It is vital to have a suitable **environment** ready with the necessary characteristics to ease the change of medication or any other modification (calm, quiet atmosphere, free of stress, etc.).

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5. What not to do

- And finally, it is also important to clarify...

WHO NOT TO NOTIFY - AND WHAT NOT TO DO

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7.6. Other possible ways of dealing with suffering

If you want more information on how to deal with changes or modifications to medication, the following references may be useful:

Icarus Guide

“Harm Reduction Guide to Coming Off Psychiatric Drugs”. Published by The Icarus Project & Freedom Center.

The main aim of this guide is to inform people taking psychiatric medication of the options available to them if they decide to explore discontinuation.

http://www.willhall.net/files/ComingOffPsychDrugsHarmReductGuide2Edonline.pdf

GAM Guide (Gaining Autonomy in Medication) Canada

A personal guide to autonomous medication management offering a process of reflection and action designed to enhance understanding about medication, its role and its effects in every aspect of life. It helps the individual to recognize their needs and to be better informed to make decisions.

http://www.rrasmq.com/GAM/documentation.php

http://www.rrasmq.com/GAM/documents/GuideGAM-EN-2019.pdf

GAM Guide (Gaining Autonomy in Medication) Brazil/Guia do Moderador

Guide based on the work in the Canadian guide and adapted to the Brazilian context. It also includes a guide for the group facilitator.

https://www.fcm.unicamp.br/fcm/laboratorio-saude-coletiva-e-saude-mental-interfaces

«Saldremos de esta. Guide de salud mental para el entorno de la persona en crisis»

This guide aims to answer some of the questions that mental suffering can raise. It is conceived as a tool for family members, members of the person's social network, and people with their own experiences, and takes a collective approach to meeting their needs, shifting the focus away from the individual to resources such as care agreements, and mutual help and support groups.

http://www.infocop.es/pdf/saldremos-de-esta.pdf

«Beyond Belief: Alternative Ways of Working with Delusions, Obsessions and Unusual Experiences». Knight, Tamasin

This book provides a set of practical tools to deal with what are known in clinical terms as delusions, obsessive ideas or intrusive thoughts. Tamasin Knight experienced mental suffering and received psychiatric treatment, and in this publication she attempts to provide help to cope and live with unusual beliefs instead of focusing all efforts on trying to remove them.

https://madinspain.org/wp-content/uploads/2020/03/Mas_alla_de_las_creencias_MIAH.pdf

http://www.peter-lehmann-publishing.com/books/knight.htm

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Annexes

Annex 1. Glossary of some terms

Active substance:

The molecule in the drug that provides its therapeutic properties.

Adverse effect:

A harmful or significantly unpleasant effect caused by a drug when taken in a dosage expected to have a therapeutic (or pre-emptive or diagnostic) effect, which justifies reducing the dosage or withdrawing the drug and/or predicts danger in future administration (Laurence & Carpenter, 1998).

Apathy:

In psychology, the term has a negative meaning and refers to the affective indifference to situations that normally arouse interest or emotion (Galimberti, 2002). Apathy may be present in depressive and psychotic disorders, and "may also be present in individuals who experience routine or frustrating situations over long periods, people who have recently experienced extreme anxiety or excitement, or a deep emotional crisis, as well as those who spend long periods in hospitals, mental hospitals, prisons or other types of institutions that limit interaction with the outside world" (Galimberti, 2002: 99, our translation).

Atypical:

A new generation of antipsychotic drugs was introduced in the 1990s, known as atypical antipsychotics. They followed on from clozapine, the archetypal atypical antipsychotic, which had been withdrawn in the 1970s when it was shown to cause potentially fatal blood disorders, but was reintroduced in 1990. The success of clozapine with people considered to have 'treatment resistant schizophrenia', as well as the problems caused by the earlier drugs, especially the neurological disorder known as tardive dyskinesia, spurred attempts to develop alternatives similar to clozapine for schizophrenia and psychosis. Risperidone, also known by its trade name Risperdal, was duly approved and launched in 1994, as was olanzapine, or Zyprexa, in 1996. Quetiapine, marketed under the name of Seroquel, was approved by the U.S. Food and Drug Administration in 1994, and by the UK authorities in 1997 (Moncrieff, 2013:5).

Contraindication:

A generally accepted procedure or treatment is said to be contraindicated when a particular aspect of a patient's condition makes it dangerous or would cause an unfavorable outcome. In the literature on prescribing, a contraindication is a stronger warning than a "precaution" (or special precaution), when a drug can be used with "special care", such as closer monitoring or a lower dosage than usual (Laurence & Carpenter, 1998).

Dosage:

The specific amount of a drug that should be administered.

Emotional numbness (also known as affective flattening):

"Affective disorder characterized by a general impoverishment of emotional reactivity, which never matches the stimulus. A person with affective flattening is usually described as monotonous, emotionally listless, lacking vigor, insensitive and cold. Those suffering from affective flattening describe reality as appearing strange to them and their responses therefore seem forced, false and inauthentic" (Galimberti, 2002: 100, our translation).

Generic drugs:

When the patent (held by the inventor) on a product or patented formula expires (after a period of 16 to 20 years in many countries), any company can manufacture and sell the product as a generic drug on the market (Laurence & Carpenter, 1998).

Indication:

Reason for which a drug is prescribed.

Inhibitor:

A substance that slows or suppresses a chemical or psychological reaction.

Interaction:

A relationship or reciprocal influence that can occur between two or more medications. When two or more drugs are administered at the same time, they may interact with each other. This interaction can lead to synergism or antagonism between the drugs, and sometimes to other effects.

Side effects:

The effects of a drug that are secondary to the effects for which the drug is generally classified. Effects may be minor or adverse. See Adverse effect (Laurence & Carpenter, 1998).

Therapeutic effect:

The beneficial or desired effects of a drug.

Annex 2. Abbreviations and acronyms

AMHC: Adult mental health center.

CAMHC: Child and adolescent mental health center.

DSM-IV: *Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association (APA).

EFF: effervescent.

EXP: expiration (date).

ICD-10: *International Statistical Classification of Diseases and Related Health* 10th edition, published by the World Health Organization.

PFP: Personalized Follow-up Program.

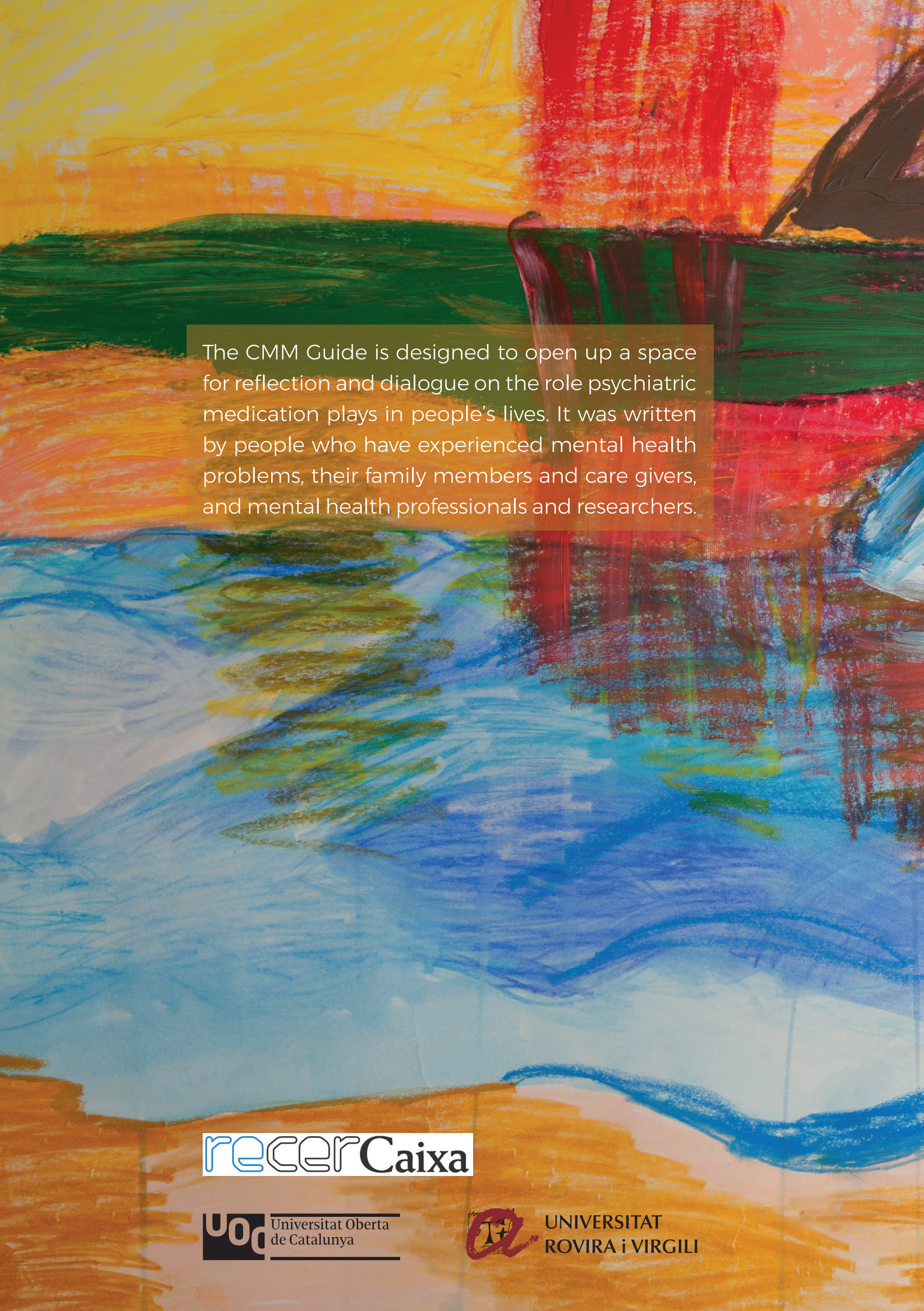
Annex 3. List of psychiatric medications

In alphabetical order by generic name

Generic name	Type of drug
Agomelatine	Antidepressant, melatonin agonist
Alprazolam	Benzodiazepine
Amisulpride	Atypical antipsychotic or neuroleptic
Amitriptyline	Tricyclic antidepressant
Aripiprazole	Atypical neuroleptic
Aripiprazole	Atypical neuroleptic, monthly injection
Asenapine	Atypical neuroleptic
Atomoxetine	Selective norepinephrine reuptake inhibitor, used in ADHD
Biperiden	Antiparkinsonian Anticholinergic
Bromazepam	Benzodiazepine
Bupropion	Antidepressant
Carbamazepine	Anticonvulsant and mood stabilisor
Chlordiazepoxide	Benzodiazepine
Chlorpromazine	First neuroleptic invented
Citalopram	Selective serotonin reuptake inhibitor (SSRI) antidepressant
Clomipramine	Tricyclic antidepressant
Clorazepate	Benzodiazepine
Clozapine	First atypical neuroleptic
Desvenlafaxine	Selective serotonin and noradrenaline reuptake inhibitor (SSNRI) antidepressant
Diazepam	Benzodiazepine
Duloxetine	Selective serotonin and noradrenaline reuptake inhibitor (SSNRI) antidepressant

Generic name	Type of drug
Escitalopram	Selective serotonin reuptake inhibitor (SSRI) antidepressant
Fluoxetine	Selective serotonin reuptake inhibitor (SSRI) antidepressant
Fluphenazine, Decanoate	First generation neuroleptic, injectable
Flurazepam	Benzodiazepine
Fluvoxamine	Selective serotonin reuptake inhibitor (SSRI) antidepressant
Gabapentin	Anticonvulsant and mood stabilisor
Haloperidol	First generation neuroleptic
Imipramine	Tricyclic antidepressant
Lamotrigine	Anticonvulsant and mood stabilisor
Levomepromazine	First generation neuroleptic
Lithium carbonate	Mood stabilizer
Lorazepam	Benzodiazepine
Lormetazepam	Benzodiazepine
Methylphenidate	Psychostimulant
Mirtazapine	Atypical antidepressant
Modafinil	Psychostimulant
Nortriptyline	Tricyclic antidepressant
Olanzapine	Atypical neuroleptic. Zypadhera is the prolonged release formulation for hospital use
Oxcarbazepine	Anticonvulsant and mood stabilisor
Paliperidone Palmitate	Atypical neuroleptic, injectable
Paroxetine	Selective serotonin reuptake inhibitor (SSRI) antidepressant
Perphenazine	Atypical neuroleptic
Pimozide	First generation neuroleptic

Generic name	Type of drug
Pregabalin	Anticonvulsant
Procyclidine	Anticholinergic antiparkinsonian
Propranolol	Antihypertensives, beta blocker, prescribed akathisia and trembling.
Quetiapine	Atypical neuroleptic
Risperidone	Atypical neuroleptic
Risperidone	Atypical neuroleptic, injectable
Sertindole	Atypical neuroleptic
Sertraline	Selective serotonin reuptake inhibitor (SSRI) antidepressant
Topiramate	Anticonvulsant and mood stabilisor
Trazodone	Heterocyclic antidepressant
Triazolam	Benzodiazepine
Trihexyphenidyl	Anticholinergic antiparkinsonian
Valproic acid/ sodium valproate	Anticonvulsant and mood stabilizer
Venlafaxine	Selective serotonin and noradrenaline reuptake inhibitor (SSNRI) antidepressant
Ziprasidone	Atypical neuroleptic
Zopiclone	Sedative
Zuclopenthixol decanoate	First generation neuroleptic. Depot- prolonged effect injectable; Acuphase- rapid effect injectable



The CMM Guide is designed to open up a space for reflection and dialogue on the role psychiatric medication plays in people's lives. It was written by people who have experienced mental health problems, their family members and care givers, and mental health professionals and researchers.

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