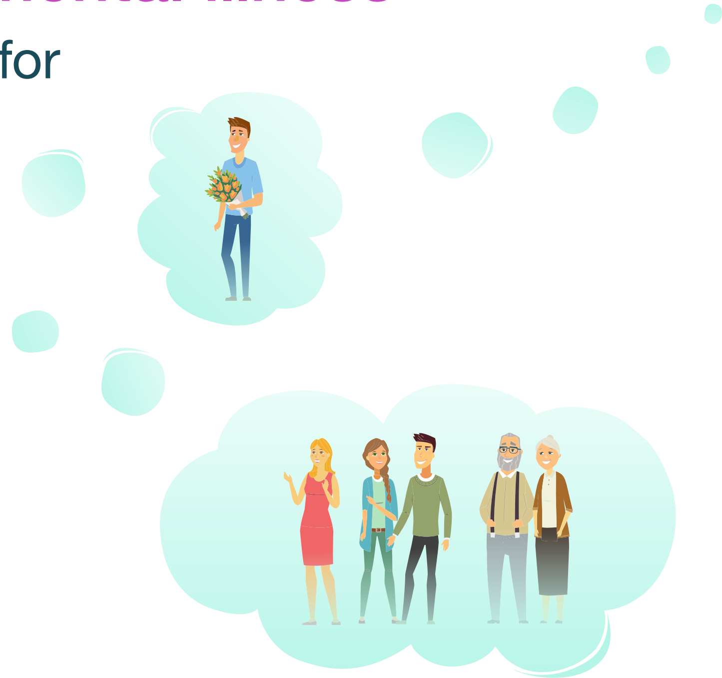
Having children
while living with mental illness
Information pamphlet for patients



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Editors and Authors

Authors from Psychiatrie St.Gallen

Dr. med. Jacqueline Binswanger
MSc Rahel Altwegg

Authors from the Dialog Ethik Foundation

Dr. theol. Ruth Baumann-Hölzle
Dr. sc. nat. Daniel Gregorowius

Other authors

Dr. med. Antje Heck, Psychiatrische Dienste Aargau
Prof. Dr. med. Erich Seifritz, Psychiatrische Universitätsklinik Zurich

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Contacts:

Stiftung Dialog Ethik:
Dr. theol. Ruth Baumann-Hölzle
Stiftung Dialog Ethik
Schaffhauserstrasse 418
8050 Zurich, Switzerland
Tel.: +41 (0) 44 252 42 01
info@dialog-ethik.ch

Kompetenzbereiche Gynäkopsychiatrie:
Psychiatrie St.Gallen
Bahnhofstrasse 18
9435 Heerbrugg, Switzerland
Tel.: +41 (0) 58 178 77 00
heerbrugg@psychiatrie-sg.ch

Praxis Dr. med. Jacqueline Binswanger:
Dr. med. Jacqueline Binswanger
Seeblickstrasse 15
9306 Freidorf, Switzerland
Tel.: +41 (0) 76 581 38 68
praxisbinswanger@hin.ch

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Preface

Dear reader,

This pamphlet is intended for women of child-bearing age who have been diagnosed with depression, bipolar disorder or schizophrenia. These mental illnesses often emerge in episodes and are frequently treated using psychotropic drugs. However, this pamphlet is also suitable for women with other mental illnesses and contains helpful information for women without a psychiatric diagnosis who want to have children. It offers a lot of important information for all women of child-bearing age who are considering having children. Having a child is always a major change in the life of you and your partner, regardless of your relationship and sexual orientation. A mental illness only adds to the complexity of the situation. The decision whether or not to have children is a deeply personal one. The information and questions in this pamphlet aim to assist you in your decision about whether or not you should have children.

The pamphlet was created by a group of experienced specialists from the fields of medicine (psychiatry, gynaecology, general internal medicine, genetics), psychology, ethics and law. Latest findings from international specialist literature on psychology, psychiatry, pharmacology and genetics were incorporated. The creation of the pamphlet was overseen by an interprofessional team of experts. See the appendix for more background information about the pamphlet.

The pamphlet is divided into three sections:

- The first section focuses on the decision whether or not to have children.
- The second section provides information on the specific topics and issues related to mental illness and pregnancy.
- The third section about responsible parenthood contains a series of questions for all women of child-bearing age.

It is important to consider that many pregnancies occur unplanned. Studies suggest that this is the case in up to 50% of pregnancies[1,2]. Therefore, it is advisable for all women of child-bearing age to consider whether they want to have a child or wish to actively prevent pregnancy for the time being.

If you are a woman of child-bearing age and you are receiving treatment for a mental illness, we recommend discussing your desire to have children with the attending specialist. If you feel that the attending specialist (psychiatrist, gynaecologist, general practitioner) does not take your feelings on the matter, or the matter itself, seriously or is generally not supportive of you becoming a mother, you can seek a second opinion from another specialist.

It is helpful to talk to the attending specialist, provided that they have appropriate expertise in preconception counselling. This could be your general practitioner, gynaecologist, psychologist or psychiatrist. Family counselling clinics can also help you clarify any questions about having children. You find some addresses in the appendix to this pamphlet.

Along with this pamphlet, specialists receive expert recommendations entitled “Integrated psychiatric psychotherapeutic preconception counselling for women of child-bearing age” (available as a long or short version, but only in German language), which draw and expand on the information and questions in this pamphlet. The aim is for the specialist to provide you with sound information, advice and support to help you make the right decision for you in your specific situation.

We hope that this pamphlet helps you decide whether or not to have children.

Ruth Baumann-Hölzle, Jacqueline Binswanger,
Daniel Gregorowius and Rahel Altwegg

Zurich, September 2021

Specialists can find recommendations related to this pamphlet on the following websites:

Dialog Ethik Foundation:
www.dialog-ethik.ch/praekonzeptionelle-beratung

Psychiatrie St.Gallen:
www.psychiatrie-sg.ch/gynaekopsychiatrie

1 Deciding whether to have children

Throughout your life, you will make many decisions that have major consequences. The decision whether or not to have children is one such example. Nowadays, it no longer needs to be left to chance whether or not you have a child; you can consciously decide for or against it. Have you already asked yourself whether you want children?

The following questions can help you decide whether or not to have children:

1. Am I currently actively considering having a child and becoming a mother?
2. Do I feel a strong need to have a child?
3. Does my partner want a child or children?
4. Do the people in my social environment expect me to have children?
5. What do I hope a child will bring to my life?
6. What do I want my child's life to look like?
7. Am I worried or are there concerns about life with a child?
8. What could lead me to decide not to have children?
9. What would it mean for me not to have children?
10. Does my mental illness influence my desire to have children? If so, how?

Do I want

a child?

I have a **psychiatric diagnosis.** Should this influence my decision whether or not **to have children?**

2 Mental illness and parenthood

Most women worry about what a pregnancy could entail and how it could affect their life. If a woman has been diagnosed with a mental illness, additional questions need to be asked: Will pregnancy affect the mental illness? Will the mental illness affect the development of the child?

If the woman has received professional psychiatric treatment and care and has a supportive family network (parents, grandparents, etc.), a child can develop well with a mother experiencing mental illness. However, if these conditions are not met, the welfare of the child may be threatened. As such, a mental illness can result in direct risks for the child (e.g. birth complications, low birth weight3), as well as indirect risks associated with the increased stress and reduced mental resilience experienced by the mother, the mother's weakened relationship and reduced engagement with the child, and even her increased suicide risk.

Those experiencing mental illness benefit from open discussion with specialists about the possible effects of the illness and the limitations it causes. This includes considering whether the patient is capable of caring for her child alone or whether additional assistance is required, for example in the form of family support. The people in the mother's social environment – especially the father/partner – are a vital source of support and relief in everyday life. To prevent relapses, it is important that people in the mother's social environment look out for warning signs and that specialists are available to provide assistance. It is also important that women experiencing mental illness can count on the people around them, and that they receive adequate support and relief to allow them to care for themselves and their children. If you have a severe or chronic mental illness, you should consult the attending specialist in advance to determine and plan how exactly care for the child can be arranged, for example in the event that you require hospital admission. It is very important that you do not reduce or stop taking any of your medications without first consulting a specialist. This can make a mental illness worse under certain circumstances[4,5,6].

Therefore, it is important that you inform your gynaecologist of your mental illness, even if you are not showing any symptoms. Receiving well-founded advice early on – in particular regarding the intake of medications during pregnancy and breastfeeding – is very helpful. The following chapters contain important information about individual illnesses and medications.

2.1 Depression and parenthood

2.1.1. General information

The time and age at which people experience depressive disorders vary greatly. Half of all people living with depression experience it before the age of 31[7]. Depression is characterised by its episodic nature, which means that the symptoms are experienced in phases (episodes). However, some people are chronically depressed, meaning that individual episodes are not intermittent but instead the symptoms are experienced continuously. A depressive episode, during which the illness exhibits its specific symptoms, can vary in severity. After this episode, the symptoms may disappear entirely or residual symptoms may remain which increase the risk of another episode[8]. The symptoms will then return in what is known as a "relapse". Half of the patients suffering from depression will experience at least one further acute phase[9] of the illness in their lifetime, which will significantly increase the probability of a relapse[10]. Some people experiencing depression also suffer from other mental illnesses, such as anxiety and panic disorders, obsessive-compulsive disorder (OCD) or addiction[11]. These conditions can make it even more difficult to cope with depression and function in everyday life.

2.1.2. Pregnancy, childbirth, post-partum period and depression

Depressive episodes can also occur during pregnancy. The incidence is roughly the same as among non-pregnant women[12], with about 12% of women affected. If you are experiencing a known case of depression during pregnancy and you suddenly stop taking your medications (antidepressants or mood stabilisers), this will significantly increase your risk of a relapse. Statistically speaking, as many as seven out of ten people may experience such a relapse[13].

The risk of a depressive episode (first occurrence, recurrence, or worsening of depressive symptoms) increases significantly after childbirth[14]. This is known as post-partum (Latin for "after childbirth") depression and affects about 15% of women. One of the main risk factors for this condition is the occurrence of depressive symptoms during pregnancy[15]. If you are already experiencing depressive symptoms, these may be worsened after childbirth due to hormonal processes and difficulty adjusting to your new life circumstances[16].

2.1.3. Care for the well-being of the mother and child

Most women with a depressive disorder have already experienced one or several episodes. This comes with a degree of "expertise" concerning their condition. The life circumstances of each woman experiencing depression, as well as the way the condition presents itself, vary greatly from person to person. As such, there is no blueprint for dealing with pregnancy, childbirth and the post-partum period while living with depression. It is important to take into account your personal situation early on and discuss with your psychologist or psychiatrist the risk of a new depressive episode or of current symptoms worsening. They can explain the various ways you can get support and what to consider regarding medication.

Do I have enough information about diagnosis of **depression** and **pregnancy?** What questions do I still want answers to?

2.2 Bipolar disorder and parenthood

2.2.1. General information

Bipolar disorders – which are marked by the occurrence of depressive and manic episodes – have highly varied courses. Most sufferers of bipolar disorder will experience repeated episodes[17]. Many of these people will exhibit residual symptoms after an episode, which can affect their lifestyle and their ability to perform tasks, while also promoting the occurrence of another episode[18]. Those experiencing bipolar disorder often suffer from another mental illness (such as anxiety, OCD or substance abuse) which can cause additional symptoms and limitations[19]. The course and prognosis affect one's lifestyle and desire to have children.

2.2.2. Pregnancy, childbirth, post-partum period and bipolar disorder

During pregnancy, there is no increased risk of an initial occurrence or a recurrence of bipolar disorder. However, the risk increases significantly if you suddenly stop taking your medication(s) while planning a pregnancy or during pregnancy[20].

After childbirth, by contrast, the probability of an initial occurrence or a recurrence increases significantly[21]. Women with bipolar disorder are at high risk of developing severe psychosis after childbirth, either as a first diagnosis or a recurrence[22]. Even with appropriate treatment involving medication, this is often unavoidable[23]. Symptoms usually appear within the first two weeks after childbirth. In the case of severe symptoms, there is a major risk to the health of mother and child[24]. Therefore, it is unequivocally recommended that mothers experiencing bipolar disorder give birth in a hospital with an adjoining consultation-liaison psychiatry department. With a consultation-liaison service, a psychiatric specialist is present in the hospital, so that the woman can receive psychiatric treatment during childbirth and the post-partum period.

2.2.3. Care for the well-being of the mother and child

Most incidences of bipolar disorder occur during adolescence or early adulthood, meaning most affected women who wish to have children will already have experienced manic and depressive episodes, which gives them a degree of expertise in their own condition[25]. Effective management of the condition with the help of specialists and careful adjustment of medication dosages are vital. The mother's social environment is also essential in supporting her after childbirth to help her cope with everyday life. The father/partner has an especially important role to play in the weeks and months after the birth of the child. Curtailing stimuli, adequate sleep and identification of individual early warning signs of relapse are essential tools to ensure the welfare of mother and child. In the event of a severe course, for example, where the mother has to be admitted to the hospital, plans for childcare should be made in advance.

Do I have enough information about **bipolar disorder diagnosis** and **pregnancy?** What questions do I still want answers to?

2.3 Schizophrenia and parenthood

2.3.1. General information

More than two thirds of schizophrenia patients develop the condition before their 31st birthday[26]. The course of schizophrenia takes various forms. For about one third of those affected, symptoms will subside and never return after the initial episode, which may be more or less acute or pronounced[27]. The other two thirds will experience further episodes in years to come[28]. This can follow different courses. Either the symptoms subside completely between episodes so that everyday life can be managed independently again, or the patient experiences constant, but less severe symptoms between episodes which limit their ability to cope with everyday life. In about 5–10% of cases, the condition becomes chronic, meaning it is experienced continuously without distinct episodes[29].

People experiencing schizophrenia may present with other mental afflictions that could have a negative effect on the course of the condition. These include abuse of and dependence on substances (especially tobacco, alcohol and cannabis), depression and suicidality, as well as OCD, post-traumatic stress disorder (PTSD) and anxiety disorders.

2.3.2. Pregnancy, childbirth, post-partum period and schizophrenia

There is no increased risk of developing schizophrenia during pregnancy and up to twelve months after childbirth[30]. However, if a patient stops taking medication designed to help stabilise her condition, her risk of relapse is greatly increased[31]. Women with schizophrenia are at heightened risk of complications during pregnancy and childbirth[32]. The child often has a lower birth weight[33]. This could be explained by lower economic status and the greater presence of known risk factors, such as smoking, as well as alcohol and drug consumption[34]. It could also be the case that the condition makes it harder for the woman to access screening during pregnancy and after birth[35]. In rare cases, the mother may deny the existence of the pregnancy and thus endanger herself and the child[36].

2.3.3. Care for the well-being of the mother and child

Many women who want to have children have already experienced episodes of schizophrenia. They are able to integrate the condition into their life plans. However, severe or chronic cases can make this difficult, or even impossible. The people in the mother's social environment – in particular the father/partner – are vital sources of support and relief in everyday life. To prevent relapse, it is important for these people to look out for warning signs and for specialists to be available.

Do I have enough information about **schizophrenia** diagnosis and **pregnancy?**
What questions do I still want answers to?

2.4 Psychotropics during pregnancy and breastfeeding

All illnesses, whether physical or mental, must be identified and treated. They can occur at any stage of life, including pregnancy and breastfeeding. What's different about these specific stages of life is that the decision for or against a certain form of treatment directly and indirectly affects the well-being not only of the woman, but also of the child. Therefore, when planning treatment for women of child-bearing age, it is essential to consider their desire (or lack thereof) to have children. Extra care must be taken when deciding whether to use medications. This section provides important information about treating mental illness with medications (psychotropics) during pregnancy and breastfeeding. However, it is no substitute for specialist consultation and a personalised therapy programme with a psychiatrist.

The goal of treatment is to bring about relief from symptoms and mental stability while helping the patient cope with everyday life. It can also be used to protect against relapse. To help you decide whether to use medication, you should consult the relevant specialist, that is, your psychiatrist or gynaecologist. Many different factors must be considered when choosing a medication, such as the type of condition (diagnosis), its severity and frequency (first occurrence or recurrence), as well as any prior experience with medications.

For women of child-bearing age, it is also important to assess whether the medication will pose risks to the child during pregnancy and breastfeeding. Apart from medication, certain therapies designed to improve self-care or regular activities (sport, meditation, etc.) can help prevent relapse.

This decision and, if applicable, the choice of medication, must be based on a careful assessment of the benefits and risks. Since the severity and course of an illness varies greatly from person to person, this assessment must be made on a case-by-case basis.

2.4.1. Benefits

Medication is designed to relieve symptoms while improving the mental state and mental stability of the patient. When free of symptoms, people with mental illnesses feel better able to perform tasks, deal with stress and function independently in everyday life. Medication can often prevent the need for more drastic measures, such as inpatient treatment, or allow such measures to be cut short. All of this benefits the child.

Can my **medication** harm my **child?**

2.4.2. Risks

If medications are taken during pregnancy and breastfeeding, their effects on the child must always be assessed. The risk of the medication causing deformities or physical/mental developmental disorders in the child must be assessed and ruled out in advance.

Additionally, **untreated mental illnesses** pose direct risks to the child, such as birth complications or low birth weight[37]. Furthermore, there are also potential indirect risks if the patient experiences increased stress or reduced ability to perform tasks, has a weak bond and reduced engagement with the child, or is at an increased suicide risk. When deciding whether to use medication, it is essential to perform a risk-benefit analysis, taking into account the risks to mother and child posed by the condition itself and by the drug therapy.

You should never stop taking medication suddenly. Once you have responded well to a medication, you should not change it without first consulting a medical specialist – usually your psychiatrist – as this may cause the condition to get worse[38,39,40].

2.4.3. Approval

Psychotropics used during pregnancy and breastfeeding are dispensed for “off-label use”, which means that they are not officially authorised by Swissmedic, Switzerland’s authority for therapeutic products. This also applies to all other medications. A key reason that there is no official authorisation for use during pregnancy and breastfeeding is the lack of systematic comparative studies on these medications. Ethics prevent such studies being conducted on unborn children and pregnant women. Furthermore, the lack of official authorisation represents a legal safeguard for the distribution company. However, it can cause uncertainty among patients and specialists – especially if there is no evidence of harmful effects on children from clinical experience.

When it comes to prescribing medications, it is important to evaluate every situation individually. Off-label use does not mean a medication cannot be administered. Rather, it means that the risk-benefit analysis cannot be based solely on the information in the package insert, and that other specialist information and advice centres, such as those listed below, must be consulted. With the extensive selection of case reports and other studies conducted to date, there is no shortage of data available on the effects of medications during pregnancy and breastfeeding. This enables an accurate assessment of a drug's suitability for use during pregnancy and breastfeeding[41]. There are various services operated by qualified experts that provide information about the benefits and risks of medications.

- **Embryotox** is provided in Germany by specialists from a range of fields, such as gynaecologists, pharmaceutical specialists and psychiatrists. Embryotox offers personal consultation and maintains a free-of-charge online database. You can access this service at www.embryotox.de.
- At **Reprotox,** Dr. med. Wolfgang Paulus from Ulm University Medical Center draws on a database to advise patients and specialists. For additional contact details, visit www.uniklinik-ulm.de/frauen-heilkunde-und-geburtshilfe/schwerpunkte/geburtsmedizin/medikamentenberatung.html
- In Switzerland, Dr. med. Antje Heck offers **consultation on "Medications during pregnancy and breastfeeding"** at Psychiatrische Dienste Aargau. In a personal consultation, you can discuss the use of medication when trying for children, as well as during pregnancy and breastfeeding, jointly assess the risks and determine the best course of action. The contact details can be found at www.pdag.ch/fuer-patientinnen-patienten-und-angehoerige/angebote-fuer-kinder-und-jugendliche/offers/spezialsprechstunde-medikamente-in-schwangerschaft-und-stillzeit/. You can register for the consultation via email: schwangerschaft@pdag.ch.
- Additionally, **gynaeco-psychiatry services** are available in some cantons which cover topics such as medications as part of a comprehensive treatment concept. If you are interested in gynaeco-psychiatry services, it is best to enquire with your regional psychiatric outpatient clinic.

If you want to know more about a medication, you can start by contacting Embryotox and then discuss the information you receive there with your psychiatrist. The database is updated continuously. Comprehensive collections of detailed single-case reports allow professional, evidence-based assessment of the risks of individual drugs.

There is a large number of different drug groups which, as used until now, **do not result in any increased risk of deformity** or childhood developmental disorders. These drugs pose a relatively low risk to the mother and child while potentially offering major benefits. Generally speaking, the longer a drug has existed and the more it has been used, the more data is available on it, meaning recommendations are based on a larger body of data. This can help to choose an appropriate medication within the various drug groups. At the same time, the choice of drug depends on the condition in question and the personal factors of the patient.

To be able to monitor the risk posed by a drug during pregnancy, women are often advised not to use more than one medication. Nonetheless, depending on the symptoms and severity of the illness, treatment with several substances is often necessary and useful in maintaining or restoring mental stability.

Table 1 contains a list of the major psychotropics. The "agent of choice" column contains the drugs that have been extensively tested in use and do not harbour any additional risks beyond the rate of spontaneously occurring deformities. "Tolerable" describes alternative agents with the same spectrum of action, about which a good amount of data is available, but whose effects have not been studied quite as much as with the agents of choice. The "not recommended" column lists agents proven to be harmful to the development of children.

The table also incorporates clinical experience of certain medications. These medications are written in italics and supplemented with a footnote.

When taking any medication which affects the nervous system in the brain and spinal cord, such as psychotropics, the newborn baby may have short-lived symptoms after birth in what is known as "poor neonatal adaptation"[42]. This can manifest itself in the form of overexcitability, sleep disorders, shrill crying and drowsiness. These symptoms go away on their own after the first few days and have no long-term negative effects on the child's development. In our experience, poor neonatal adaptation is very rare in newborns after intake of medications from the SSRI class (selective serotonin reuptake inhibitors, such as citalopram, escitalopram and sertralin). After intake of medications from the SSNRI class (selective serotonin and noradrenaline reuptake inhibitors), poor neonatal adaptation may occur more frequently depending on the dose, but it is not usually harmful. However, if the mother has a benzodiazepine dependency or regularly takes "Z-drugs" (such as zolpidem), these symptoms can last longer and the newborn may require paediatric treatment[43].

If medications are taken regularly during pregnancy, we recommend giving birth at a hospital with a neonatal ICU (intensive care unit for newborns) so that the baby can receive effective, specialised care. This also means that the mother and child can be treated in the same place, which avoids early separation.

It is also a good idea to discuss your intake of the required medications with your prescribing doctor at regular intervals throughout the course of your pregnancy. This is important not only because your mental health can deteriorate during pregnancy, but also because a pregnant woman's blood often contains a lower level of a medication than before the pregnancy. This sometimes requires the dosage of your medication to be increased to maintain the same effect. If you take mood stabilisers, your blood levels of the drug should be tested during pregnancy to allow appropriate adjustment of the dose. Under no circumstances should you reduce your dose or stop taking a medication shortly after finding out about your pregnancy without first consulting a specialist.

Throughout the entire pregnancy, good communication between the attending physicians from every discipline (e.g. psychiatry, gynaecology) is essential. Before the birth, contact should be made with the maternity clinic and the medication should be planned for the time around the birth and the breastfeeding period. Many different psychotropics can also be taken during breastfeeding. If additional sleeping aids or other medications are needed, you can discuss the option of weaning or partial weaning. It is also important to ensure in good time that the new mother has a network of people ready to help her if her condition worsens. In this case, the family or midwife should discuss ways of supporting the mother as well as outpatient or inpatient treatment options and, if necessary, make use of them early.

Previous research has shown that the mother's mental health, social environment and bond with her child are just as significant to the child's healthy long-term development as the effects of psychotropics during pregnancy[44]. This demonstrates once more how important it is for the mother to be in good health and a good mental state.

Table 1: Agent of choice according to treatment indication based on Dathe & Schaefer (2019)[45]

(please note: when choosing a medication, you should consult the latest information at www.embryotox.de for comparison)

Indication (reason for the medication)	Agent of choice	Tolerable	Not recommended (contraindication)	Note
Depressive symptoms, avolition	Sertraline, Citalopram, Escitalopram	Other established antidepressants[46]		Poor neonatal adaptation[47] is generally unlikely after SSRI intake[48]
Depressive symptoms, agitation	Amitriptyline, Mirtazapine	Other established antidepressants[49]		Potential for poor neonatal adaptation in newborns
Bipolar disorder	Quetiapine, Lamotrigine	Lithium Other established antipsychotics[50]	No valproic acid as mood stabiliser (relapse prevention)	Do not stop using lithium once you reach a stable mental state; potential for poor neonatal adaptation in the newborn, especially with lithium
Psychotic symptoms	Quetiapine, Olanzapine, Risperidone, Aripiprazol, ***Haloperidol***[51]	Other established antipsychotics[52]		Potential for poor neonatal adaptation in newborns
Sleep disorders, stress, restlessness	Diphenhydramine, ***Amitriptyline***[53], Mirtazapine, Quetiapine, ***Lorazepam***[54]	***Trazodone***[55] (long-term intake), Zolpidem, Zopiclone (short-term only)		Warning: Chronic use of benzodiazepines and Z-drugs can cause withdrawal in newborns
Anxiety disorder	Sertraline, Citalopram, ***Escitalopram***[56]	Venlafaxine extended release Other antidepressants[57]		Poor neonatal adaptation unlikely in the newborn after SSRI intake, but possible after SNRI intake
Obsessive-compulsive symptoms	Sertraline, Citalopram ***Escitalopram***[58]	Other established antidepressants[59]		Poor neonatal adaptation not very likely in the newborn

Can I
pass my condition
on to my child?

2.5 Hereditability of mental illnesses

Mental illnesses are caused by an interplay of biological, psychological and social factors. Genetic factors, which fall under the biological category, play an important role here. However, mental illnesses never have a clear, single genetic cause: our genetic makeup is merely one risk factor among many. This risk factor is also referred to as "vulnerability".

A certain genetic predisposition, or vulnerability, is not enough to trigger a mental illness on its own; it merely increases the risk of developing one under certain circumstances. Whether or not a mental illness actually develops depends on other psychological and social factors. Examples of these psychological factors include how well someone is able to cope with stress or adapt to challenging situations. Relevant social factors include the extent of stress factors in the mother's life, and whether she can control or positively influence these factors.

The ability to deal with stress and overcome challenging life situations is also known as "resilience". This is determined by biological, psychological and social factors. People with a high degree of resilience can overcome adverse conditions without succumbing to mental illness. Conversely, people with a high degree of vulnerability or less resilience can develop mental illnesses for no apparent external reason[60].

Genetics and the hereditary transmission of mental illnesses are investigated using two fundamentally different study types.

- In essence, the first study type – twin and family studies – investigates whether certain mental illnesses occur more frequently depending on the degree of kinship. The classic study model investigates the likelihood of identical twins who are largely genetically identical developing the same illness. To control for social factors, these studies also include twins who have grown up in separate families under different circumstances. These twin and family studies allow us to determine the influence of genetics on vulnerability and resilience at a certain degree of kinship. For example, some studies investigate the genetic vulnerability of the son of a schizophrenic woman or of the identical twins of a woman with depression.

- The second study type – genome-wide association studies – involves looking for individual genes and/or traits in our DNA which have been shown statistically to correlate with certain mental illnesses. This means comparing a large number of people who have a certain mental illness with people who do not have a mental illness. These studies are intended to identify individual genes or traits which are associated with the illness. In the last few years, many such studies have been conducted involving millions of healthy and ill individuals. They have found several genes and DNA components which affect vulnerability. However, the influence of these molecular changes is only relevant from a statistical viewpoint. They are not significant on a personal level, so they cannot be used as a basis for assessing individual risks. It appears that the molecular genetic make-up for the development of mental illness is very complex. It also seems to be the case that the influence on vulnerability is explained less by genes, and more by a not-yet-understood interplay between many different genes and traits in the DNA.

Our DNA is not only determined by inherited genetic information, but also affected by environmental factors. For example, strong stress factors in a person's environment can trigger changes to their DNA which result in certain genes being less strongly selected or switched off. As a result, the products of these genes – proteins, which play a vital role in the body – are reduced or no longer produced. These are known as "epigenetic" changes and are caused by factors such as difficult life experiences and chronically harmful influences. Although epigenetic research is still relatively new, we now know that vulnerability and resilience with regard to mental illness can be influenced by epigenetic factors. In other words, the inherited genetic information in our DNA cannot fully explain a person's individuality. Epigenetic influences can lessen a high genetic risk, namely by increasing resilience, and increase low genetic risks, namely by increasing vulnerability.

In summary, we know that the risk of developing a given mental illness is partially determined by genetics. But this vulnerability is just one of many factors, and it can be compensated for by a favourable interplay of biological, psychological, and social factors[61]. A much more significant risk factor for the occurrence of a specific mental illness is a prior illness. In such cases, it is important to make a well-thought-out, long-term therapy plan after recovery. This is especially important if the patient is planning a pregnancy.

The risk of someone developing depression once in their lifetime is 16–20%[62], with a family history of depression increasing this likelihood[63]. Among the general population, the risk of someone developing schizophrenia in their lifetime is 1%. With a family history, though, the risk increases significantly[64]. In this case the likelihood of developing schizophrenia and bipolar disorder is considerable: as much as 50% (vulnerability) of the risk is determined by genetic factors[65]. On the other hand, though, this also means that the remaining 50% is not determined by genetics, but rather by factors that we can influence. Through targeted support of these factors and a favourable living environment, the risk of illness can be reduced[66].

These processes are currently under research. So far, research has shown that it is not just our genes that determine what happens to us and that it is important to organise our lives in ways that are most conducive to our mental health. This is also the goal of this pamphlet. If you are trying for children, you should take time to consider how best to organise the pregnancy, birth and the period thereafter for the good of mother and child. This means that people with a heightened risk of mental illness should have an open, honest discussion with their doctor so that appropriate cautionary measures can be put in place. This can reduce the risk of an episode.

This **information** about the effect of medications and genes on a **pregnancy** is certainly important. Nonetheless, I would like my **doctor** to give me more precise information.

3 Planning for responsible parenthood

3.1 What makes a good life for me and my child?

Every mother only wants the best for herself and her child. However, different women have very different ideas of what constitutes a good life. As such, we urge you to consider what a good life would look like for you and your child, and how you and your partner would manage life as parents.

For a woman or couple, having a child is a huge change. Children can enrich your life, but they are also demanding and exhausting. Parents have to nurture, care for, raise and educate their children. Every parent has moments when they reach their limit and need help. Accepting help is not a sign of weakness – it actually shows that you have the strength to recognise your own limits and the willingness to take care of yourself and your child. Most people are happy to help and be there for others.

We all go through periods of heightened stress in life. Sometimes we find ourselves in challenging situations, or we are confronted with major changes, such as a new job. An illness or an episode can also be a major source of stress. During difficult periods such as these, it is important to thoroughly evaluate whether you are able and willing to have children in this situation and at this time.

If you still really want to have a child, it is best to arrange reliable support for the period after the birth and for your life with the child as soon as possible. During periods of heightened stress, you may find that your family and friends cannot bear the strain alone. In such cases, you should make use of other services, such as home helps, external childcare or respite care. People with mental illnesses often feel ashamed to use such services, as they want to be able to cope with life independently. But we all need help sometimes. This is normal, and it says nothing about your character. In a just and humane society, people have to be prepared to help each other in times of need. Refer to the appendix for resources and contacts that can help you find support services.

In order to have a good life with their child, the mother and father/partner must be able to deal with stressful situations in life, support each other and, if necessary, rely on help and support from external parties. Your parents, grandparents, relatives and friends can all be vital sources of assistance. It is always worth asking others for help and accepting help when it's offered to you.

We recommend that you start thinking well in advance about how childcare can be organised in the event of an acute crisis. Putting this arrangement in writing will create transparency and give your decision more weight. If the help arranged by you or the people in your social environment is not enough and the child's welfare is threatened, child protection services need to be consulted to determine your need for support and organise appropriate measures.

The following questions are designed to help you think about how you imagine a good life with your child and what you expect from life as a parent. You might find that it helps to note down your thoughts on the questions.

1. What do I consider most important for my life with a baby/infant?
2. What, in my eyes, makes a “good mother”?
3. Do I trust in my ability to take responsibility for caring for, nurturing, raising and educating my child? If so, why? If not, why not?
4. How exactly do I picture my life with a baby/infant?
5. How might my life change if I have to look after a baby/infant? How happy would I be with these changes?
6. What challenges could a baby/infant present, and how would I deal with them? Who could help me with this?
7. What about having a baby am I looking forward to?
8. What about having a baby makes me anxious? Who could alleviate this anxiety for me? And how would they do that?

Who will support and guide **my child** on the path to **adolescence?**

Can we cope with the challenges of parenthood **together?**

Will I need support from **society?**

3.2 Requirements for a good life for mother and child

Certain conditions must be met to facilitate a "good life" for you and your child. To get a good start in life, children need a trusting bond and consistent relationships with people who are committed to watching over, looking after and raising them over the course of many years. The biological mother cannot manage all of this alone.

The following prompts are designed to help you consider what conditions must be met to ensure a "good life" for a mother and her child. They may even broaden your perspective. The aim of the prompts is to help you clarify to what extent you can meet these requirements on your own or with the support of the people around you, such as family and friends. You should also consider how dependent you would be on the support of your community or certain specialist help centres. Please respond to each prompt by circling the appropriate emoji. Ultimately, these prompts are designed to provide a taboo-free space to help you clarify whether you and your partner want to fulfil a possible desire to have children or whether, in light of major life and health challenges, you wish to hold off for now or even avoid having children.

1. I currently consider my relationship with my partner to be stable enough for us to overcome the challenges of parenthood.

2. My partner and I are in a financial situation which is suitable for a life with a child if I do not require any external childcare.

3. My partner and I are in a financial situation which is suitable for a life with a child, even if I require external childcare.

4. My partner and I have already considered, or spoken specifically about, how we can manage childcare, the household and our professional lives together.

5. My partner is able and willing to directly support me in childcare, for example by changing nappies, getting up at night, keeping an eye on the child, comforting the child, regularly preparing meals for the child, stepping in during arguments, etc.

6. My partner and I already have a specific idea of how to raise our child and what we want to pass on to him/her.

7. I want to raise my child the same way I was raised.

8. I can rely on help with childcare from parents, grandparents, siblings, relatives and friends.
I have already asked these people about this, and they agreed to help.

9. I am prepared to learn how to deal with, take good care of, properly swaddle and breastfeed a baby, etc. I am also prepared to seek help for this, for example from a midwife, a maternity and paternity counsellor, or other advice centres if I have any questions.

10. I am aware that a child would greatly change my life.

11. I am confident that I will be able to cope with and support my child, even if they are unwell, crying or moody.

12. I want to be able to give my child the same upbringing I got from my mother and/or father or would have hoped for.

13. I am confident that I can be a “good mother” despite my mental illness.

14. I have already spoken with my partner about my mental illness and what it means for our child and us as parents.

15. I can cope with negative emotions and phases of illness, as I can access and accept help in challenging situations.

16. When there is no other option during periods of illness I am prepared to leave the task of childcare to my partner, parents, siblings or someone else temporarily in order to ensure my child’s well-being.

17. I will always seek help for my mental illness when I am not doing well so that I can feel better and properly care for my child.

3.3 Societal change and challenges for women and mothers

Over the last few decades, the perception of women's role in society and the expectations of mothers have changed dramatically. In Western societies such as Switzerland, we have seen ever-increasing gender equality, especially in the younger generations[67]. This has influenced career opportunities and choices made by men and women, role models in a marriage and the allocation of parenting duties. Even as equality continues to increase, both societal and self-imposed expectations of mothers/parents remain very high, sometimes higher than what men and future fathers expect of themselves in their role as parents[68].

But it is not just in terms of gender relations and parental roles that Western, industrialised countries have changed over the past few decades: Social relationships, especially between parents and children, are taking on a different form[69]. Couples used to have children for economic reasons, for example to provide security for their old age. Nowadays, though, people are motivated more by their pursuit of happiness and personal fulfilment, which having children may contribute to[70]. This has been accompanied by a changed perception of parenting: whereas an authoritarian approach used to be the norm, parents nowadays favour more egalitarian parent-child relationships and family structures[71].

Despite increasing diversity in our society, there are still prevailing views about women's role as mothers. Unrealistic expectations imposed on a woman by society or herself can be a source of uncertainty and pressure, even for women without mental illnesses. This is why you should discuss any uncertainties, worries or doubts you may have with your attending specialist, such as your psychiatrist or psychologist. You should discuss your concerns and desires with regard to having children and to what extent these relate to the expectations of society, your family and your partner. To what extent these traditional expectations affect relationships involving new gender identities is unclear and not well researched. This question would go beyond the scope of this pamphlet.

If you are sure that you want to have children and consider yourself capable of providing adequate support for your child, then you should consider the following: Do not allow relatives, friends or certain societal expectations to cast doubt on your desire to have children. Having children and experience motherhood can have a very positive effect on your well-being, provided that you receive support from your social environment when needed[72], you are adequately mentally stable and you receive proper medical care. Do not just ask your close relatives for medical help and support; you can also get help from friends, neighbours and even public authorities. It is not just up to the parents to raise a child. Their community has to help.

This pamphlet has helped me **find answers** to many questions, but also raised others. **I will** now ponder on these issues and **discuss** them with my **partner,** my **psychiatrist** and the people in my social environment.

3.4 Final thoughts

Many women and their partners feel a deep yearning to become parents. Being a parent is a huge challenge in itself, even without mental illness. Children really do turn your life upside down. And just like with all existential experiences – be it love, sickness, loss or death – it's very hard to predict how we will react to it.

Some hopes and fears will come true, while others will not. Pregnancy and parenthood, just like life itself, are full of opportunity and risk. This is the case whether you have a mental illness or not.

It is important to remember that not every child gets to start life in good health. Taking care of a child with health problems can exacerbate the challenges of parenthood.

The joy of motherhood is not a permanent state, but rather consists of repeated happy moments with their children. This positive feeling can fade in times of stress.

Only you and your partner can judge what it would mean for you to become a mother. Good parenting requires the mother and father/partner to receive support in this exceptionally responsible task. This point is illustrated very well by an old African proverb: “It takes a village to raise a child”. Therefore, you should ideally clarify in advance of a possible pregnancy who is willing and able to help you guide your child on the path to adulthood. Outside support is essential to provide a child with a good upbringing. And you, as a future mother, are entitled to this. So do not be scared to ask for help, or even demand it if necessary. The well-being of you and your child is paramount.

4 Helpful resources and contacts

Below is a list of useful websites which provide further information on this topic, as well as contacts competent to advise women who want children while experiencing mental illness. Various points of contact offer information about the support available at cantonal level. The cantonal psychiatric services can provide more information about this.

Embryotox: Pharmacovigilance and advisory centre for embryonal toxicology at Charité-Universitätsmedizin Berlin:
www.embryotox.de

Reprotox: Advisory centre for medication during pregnancy and breastfeeding – scientific focus on reproductive toxicology, Dr Wolfgang Paulus, University Hospital of Ulm:
www.uniklinik-ulm.de/frauenheilkunde-und-geburtshilfe/schwerpunkte/geburtsmedizin/medikamentenberatung.html

Kompetenzbereich Gynäkopsychiatrie, Psychiatrie St.Gallen:
www.psychiatrie-sg.ch/gynaekopsychiatrie

Marcé Gesellschaft für Peripartale Psychische Erkrankungen e.V. Dr. Luc Turmes, LWL-Klinik Herten:
www.marce-gesellschaft.de

The International Marcé Society for Perinatal Mental Health, Brentwood, USA:
www.marcesociety.com

Mutterglück!? Ostschweizer Forum für Psychische Gesundheit:
www.ofpg.ch/projekte/mutterglueck

Special consultation on medication during pregnancy and breastfeeding, Dr Antje Heck, Psychiatrische Dienste Aargau AG:
www.pdag.ch/fuer-patientinnen-patienten-und-angehoerige/angebote-fuer-kinder-und-jugendliche/offers/spezialsprechstunde-medikamente-in-schwangerschaft-und-stillzeit/

5 Recommended reading

Below is a list of literature (in English or German) which can help you to further expand your knowledge about various issues relating to the desire to have children.

5.1 Pregnancy and mental illness

Rohde, A.; Dorsch, V.; Schaefer, C. (2014): ***Psychisch krank und schwanger – geht das? Ein Ratgeber zu Kinderwunsch, Schwangerschaft, Stillzeit und Psychopharmaka.*** 1st edition. Stuttgart: Kohlhammer.

5.2 Psychopharmacology during pregnancy and breast-feeding

Briggs, G. G.; Freeman, R. F.; Yaffe, S. F. (2021): ***Drugs in Pregnancy and Lactation. A Reference Guide to Fetal and Neonatal Risk.*** 12th edition. Alphen aan den Rijn: Wolters Kluwer.

Rohde, A.; Dorsch, V.; Schaefer, C. (2016): ***Psychopharmakotherapie in Schwangerschaft und Stillzeit.*** 4th edition (fully revised and expanded). Stuttgart and New York: Georg Thieme Verlag.

5.3 Introductory ethics

Höffe, O. (2008): ***Lexikon der Ethik.*** 7th, revised and expanded edition. Munich: C. H. Beck.

Höffe, O. ***(2018): Ethik. Eine Einführung.*** 2nd, revised edition. Munich: C. H. Beck.

Panza, C.; Potthast, A. (2011): ***Ethik für Dummies.*** Weinheim: Verlag Wiley-VCH.

Pieper, A. (2017): ***Einführung in die Ethik.*** 7th, revised edition. Bern and Munich: A. Francke UTB.

5.4 Ethics in medicine

Rufer, L.; Baumann-Hölzle, R. (2015): ***Mantelbüchlein Medizin & Ethik III. Basiswissen.*** Zürich: Schulthess Juristische Medien.

Wils, J.-P.; Baumann-Hölzle, R. (2013): ***Mantelbüchlein Medizinethik I. Basiswissen.*** Zürich: Schulthess Juristische Medien.

Wils, J.-P.; Baumann-Hölzle, R. (2013): ***Mantelbüchlein Medizinethik II. Vertiefung.*** Zürich: Schulthess Juristische Medien.

5.5 Ethics in the health industry

Arn, C; Weidmann-Hügle, T. (Hrsg.) (2009): ***Handbuch Ethik im Gesundheitswesen 2: Ethik für Fachpersonen.*** Basel: Schwabe AG Verlag, EMH Schweizerischer Ärzteverlag.

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Christen, M.; Baumann, M. (Hrsg.) (2009): ***Handbuch Ethik im Gesundheitswesen 4: Verantwortung im politischen Diskurs.*** Basel: Schwabe AG Verlag, EMH Schweizerischer Ärzteverlag.

Meier-Allmendinger, D.; Baumann-Hölzle, R. (Hrsg.) (2009): ***Handbuch Ethik im Gesundheitswesen 1: Der selbstbestimmte Patient. Basel:*** Schwabe AG Verlag, EMH Schweizerischer Ärzteverlag.

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4 Russel et al. (2013) and Schiller et al. (2015).
5 Di Florio et al. (2013), cited in Kühner (2016), p. 927f.
6 Jones et al. (2014), cited in Kühner (2016), p. 930.
7 Hiroe et al. (2005), cited in DGPPN et al. (2017), p. 22.
8 American Psychiatric Association (2013), cited in DGPPN et al. (2017), p. 31.
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14 Kühner (2016), p. 926.
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41 Bergemann & Paulus (2016).
42 Dathe & Schaefer (2019).
43 Ibid.
44 Dathe & Schaefer (2019).

45 Based on Dathe & Schaefer (2019). The clinical experience that the author of the chapter and the project leaders have with certain medications is included in the table. These deviations from the original table are in italics and supplemented with a footnote.

46 This refers to other medicinal products with extensive experience of use during pregnancy, which can be viewed with the respective medicinal product on the Embryotox database.

47 cf. explanation of the term in the text.

48 cf. explanation of the term in the text.

49 This refers to other medicinal products with extensive experience of use during pregnancy, which can be viewed with the respective medicinal product on the Embryotox database.

50 cf. previous footnotes.

51 According to Embryotox, this is not the first-choice agent in cases where quetiapine or risperidone is more effective.

52 This refers to other medicinal products with extensive experience of use during pregnancy, which can be viewed with the respective medicinal product on the Embryotox database.

53 The medical authors of the pamphlet recommend that this drug be nominated as agent of choice for acute illness.

54 The medical authors of the pamphlet recommend that this drug be nominated as first-choice agent for short-term use.

55 Trazodone is not well documented with regard to use in pregnancy; reported cases show no evidence of additional harm to children. Widely used in Switzerland as a sleep-inducing antidepressant which can be considered in individual cases following a careful risk-benefit analysis.

56 The medical authors of this pamphlet recommend that this drug be recommended as strongly as citalopram.

57 This refers to other medicinal products with extensive experience of use during pregnancy, which can be viewed with the respective medicinal product on the Embryotox database.

58 The authors of this chapter and the medical authors of this pamphlet recommend that this drug be recommended as strongly as citalopram.

59 This refers to other medicinal products with extensive experience of use during pregnancy, which can be viewed with the respective medicinal product on the Embryotox database.

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8 About this pamphlet

This pamphlet was produced as part of a three-year project by the Dialog Ethik Foundation and Psychiatrie St.Gallen between November 2018 and November 2021. The project was funded in equal part by the Swiss Innovation Agency, Innosuisse and Psychiatrie St.Gallen(legal successor of St.Gallische Psychiatrie-Dienste Süd and Psychiatrie St.Gallen Nord). Swisslos Kanton St.Gallen provided additional funding for the production of the pamphlet for patients. The competence centre for gynaeco-psychiatry of the canton of St. Gallen, which advises and treats women regarding their desire for children as well as during pregnancy and the post-partum period, initiated the creation of this pamphlet. This came about because experience from consultation has shown again and again that women with mental illness tend to have a lot of questions about having children. Expertise of ethics and social sciences was sourced from the Interdisciplinary Institute for Ethics in Healthcare at the Dialog Ethik Foundation, which has been tackling ethical and social issues, conducting research and offering training and consultation for over 20 years.

In order to learn more about the needs of women, who form the basis of this pamphlet, Hildegard Huber (Dialog Ethik Foundation) interviewed over 20 women of child-bearing age with mental illness about their desire to have children and how they deal with it. Most of the women said that they were confident they would be a good mother despite their mental illness. The women said that their desire for children wanes during periods of illness and is strongest during periods without symptoms. They also reported that specialists rarely speak to them about having children, and that they would like more space for counselling and support to find answers to their questions. The attending specialists' points of view were examined in additional one-on-one interviews conducted by Daniel Gregorowius (Dialog Ethik Foundation). The results of both types of interviews were integrated into the drafting of this pamphlet, as were the results of a historic literature study on eugenics within psychiatry. The women interviewed provided valuable feedback on the first draft of the pamphlet, which was later incorporated into the revised version.

This pamphlet was created with the assistance and advice of an interprofessional advisory group comprising various experts. The advisory group consisted of Rahel Altwegg, MSc, Dr. med. Paola Barbier Colombo, lic. phil. Sabine Bitter, Dr. med. univ. Angela Brucher, MAS and Mediator SDM Jürg Engler, Dr. med. Tina Fischer, Dr. phil. Maria Teresa Diez Grieser, Sozialpädagoge FH (Social Worker, University of Applied Sciences) Bruno Gschwend, PD Dr. med. Dr. phil.

Ulrich Hemmeter, Pflegeexpertin HöFa II/FH/MAS (Nurse practitioner, professional education institution II/University of Applied Sciences/MAS) Hildegard Huber, Dr. med. Anette Lang-Dullenkopf, Prof. Dr. med. Brigitte Leeners, PD Dr. med. Thomas Maier, Dr. med. Jürg Nadig-Lüdy, Dr. med. lic. theol. Diana Meier-Allmendinger, Dr. med. Jürg Pfisterer-Graber, MAS Rosa Plattner, Mag. Dr. BA. Beate Priewasser, Dr. med. Silvia Reisch-Fritz, lic. phil. Elena Rezzonico and MA Joel Walder. Other experts consulted for the creation of the pamphlet were Dr. med. Antje Heck, Prof. Dr. med. Erich Seifritz, Pauline Bihari Vass, BSc, and Adelheid Lang, MSc. Expertise on legal matters came from Prof. Dr. iur. utr. Brigitte Tag. Prof. Dr. pharm. Ursula von Mandach provided advice for the revision of the pharmacological section for the 2nd edition. Some members of the advisory group and external experts became co-authors of the pamphlet. Dr. med. Paola Barbier Colombo also helped us prepare the creation of the pamphlet. She was part of the interprofessional team that conducted the project “Trying for children as a woman with mental illness”, as part of which this pamphlet was created.

9 How to get the pamphlet

This pamphlet "Having children while living with mental illness – Information pamphlet for patients" is available in digital form.

9.1 Where to find the digital version

This pamphlet is available in digital form on the following websites:

Stiftung Dialog Ethik
Schaffhauserstrasse 418
CH-8050 Zurich
Tel.: +41 (0)44 252 42 01
Fax: +41 (0)44 252 42 13
Email: info@dialog-ethik.ch
Website: www.dialog-ethik.ch

Websites offering the digital version of the pamphlet:

Dialog Ethik Foundation:
www.dialog-ethik.ch/praekonzeptionelle-beratung

Psychiatrie St.Gallen:
www.psychiatrie-sg.ch/gynaekopsychiatrie

9.2 Use in consultation

This pamphlet can be used by your doctor or psychotherapist as part of psychiatric psychotherapeutic preconception counselling. Speak to your attending specialist about this possibility. We recommend that specialists observe the recommendations in this pamphlet. These are available as recognised treatment recommendations in both short and long versions and provide specialists with additional information. The websites listed above contain detailed information on the topic for you and your attending specialist.

10 Legal notice

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Authors: Dr. theol. Ruth Baumann-Hölzle, Dr. med. Jacqueline Binswanger, Dr. med. Antje Heck, Prof. Dr. med. Erich Seifritz, Dr. sc. nat. Daniel Gregorowius, MSc Rahel Altwegg

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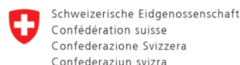

Kanton St.Gallen SWISSLOS

This information pamphlet for patients is supported by the following societies and leagues.

SGPP – Swiss Society of Psychiatry and Psychotherapy (Schweizerische Gesellschaft für Psychiatrie und Psychotherapie)

www.psychiatrie.ch/sgpp/

SGGG – Swiss Society of Gynaecology and Obstetrics (Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe)

www.sggg.ch

pädiatrie schweiz – expert association for paediatrics

www.paediatrieschweiz.ch

SGKJPP – Swiss Society of Child and Adolescent Psychiatry and Psychotherapy (Schweizerische Gesellschaft für Kinder- und Jugendpsychiatrie und -psychotherapie)

www.sgkjpp.ch

PSY & ASd SGPP SSPP SSPP

gynécologie suisse
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Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe
Società Svizzera di Ginecologia e Ostetricia

pädiatrie schweiz
Die Fachorganisation der Kinder- und Jugendmedizin

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Specialist consultation: This pamphlet was created with the collaboration and advice of an interprofessional advisory group. The advisory group consisted of Rahel Altwegg, MSc, Dr. med. Paola Barbier Colombo, lic. phil. Sabine Bitter, Dr. med. univ. Angela Brucher, MAS and Mediator SDM Jürg Engler, Dr. med. Tina Fischer, Dr. phil. Maria Teresa Diez Grieser, Sozialpädagoge FH Bruno Gschwend, PD Dr. med. Dr. phil. Ulrich Hemmeter, Pflegeexpertin HöFa II/FH/ MAS Hildegard Huber, Dr. med. Anette Lang-Dullenkopf, Prof. Dr. med. Brigitte Leeners, PD Dr. med. Thomas Maier, Dr. med. Jürg Nadig-Lüdy, Dr. med. lic. theol. Diana Meier-Allmendinger, Dr. med. Jürg Pfisterer-Graber, MAS Rosa Plattner, Mag. Dr. BA. Beate Priewasser, Dr. med. Silvia Reisch-Fritz, lic. phil. Elena Rezzonico and Joel Walder, MA. Other experts involved in the creation of the pamphlet were Dr. med. Antje Heck (co-author of the explanations about psychotropics) and Prof. Dr. med. Erich Seifritz (co-author of the explanations about genetics and epigenetics). The creation of the pamphlet (questions about attachment research) was also overseen by Pauline Bihari Vass, Bsc, and Adelheid Lang, MSc (together with Mag. Dr. BA. Beate Priewasser). Additional expertise on legal matters came from Prof. Dr. iur. utr. Brigitte Tag. Prof. Dr. pharm. Ursula von Mandach provided advice for the revision of the pharmacological section for the 2nd edition.

Sources: The pamphlet was created based on the latest findings by the authors in collaboration with the people listed under “Specialist consultation”. The contents of the pamphlet are based on the detailed long version of the recommendations for specialists titled “Integrated psychotherapeutic preconception counselling for women of child-bearing age”. In the run-up to the creation of the brochure and the recommendations (long and short versions), more than 20 interviews were conducted with affected women, as well as additional individual interviews with attending physicians. The scientific sources consulted for the pamphlet were selected and used based on the criteria of evidence-based medicine. These sources are listed under “References”. The women interviewed were later asked to provide feedback on an initial version of the pamphlet in order to improve the informative content.

Quality control: The quality control for the pamphlet was carried out by an interprofessional advisory group and other external experts (see the notes under “Specialist consultation”). The pamphlet was created based on the criteria of evidence-based medicine and the “Quality criteria for patient information materials and decision-making aids” jointly developed by the Dialog Ethik Foundation and the Swiss Medical Association (see Dialog Ethik Foundation & FMH 2018). An earlier version of the pamphlet was checked as part of a networking project with the Swiss Medical Association.

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