

# Questionnaire for Caregivers

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## INTRODUCTION

One of your loved ones has been admitted to our clinic. We are committed to his or her recovery, but also to your well-being as a caregiver for a young person experiencing a first episode of psychosis.

The purpose of the following questionnaire is to understand your perspective on what your loved one is going through and to identify what you need to continue supporting him or her. Taking the time to get to know you will greatly help us tailor our approach. It is also a way to include you in the team supporting your loved one, while respecting your boundaries.

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## CARE PLAN

A care plan will be developed with your loved one during his or her appointments with the care team, in complete confidentiality. If your loved one would like you to be involved in decision-making, you may attend certain appointments and share your perspective. Completing this questionnaire will help you prepare.

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## FREEDOM AND CONFIDENTIALITY

Answering or not answering the questions will not change the quality of the support offered to your loved one or to you. All the information you provide in this questionnaire will remain confidential, in accordance with the law. Once the questionnaire is completed, you can choose how your answers will be recorded and shared. You will have the option of keeping a copy of your answers for yourself only, without them being recorded elsewhere or shared.

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On what date was your loved one admitted to the PPEP clinic?\*

If you are not sure of the exact date, please indicate the 1st of the month.

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Does your loved one allow you to communicate with the treatment team (e.g., agree to you participating in joint meetings with them and the doctor, or to the healthcare professional sharing certain information about their treatment with you)?\*

Yes    No    Don't know    Prefer not to answer

## Your loved one's needs

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What topics do you feel are most important to discuss at this time in order to help your loved one?\*

You may choose up to 5.

- Physical health (uncontrolled illnesses, difficulties in taking care of one's health, etc.)
  - Mental health (fear of psychosis relapse, suicidal ideation, stress management, anxiety management, etc.)
  - Housing situation (maintenance, safety, sanitation, budget, etc.)
  - Social isolation (loss of friends, loneliness, distancing from family, difficulty forming relationships, etc.)
  - Risky behaviors (drug and alcohol use, criminal activity, risky sexual behavior, bad company, etc.)
  - Problems managing daily life (administrative procedures, organizing schedules, grocery shopping, independence, personal hygiene, etc.)
  - Stigma and discrimination (racism, mental health, sexual orientation, gender identity, etc.)
  - Spirituality (beliefs, practices, associations, habits, etc.)
  - Other
  - Prefer not to answer
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Comments:

In your opinion, what may have caused your loved one's health to deteriorate or his/her admission to the PPEP clinic (for young adults who have had a psychotic episode) and/or hospitalization?\*

You may choose up to 3.

- Stressful situations
- Consumption
- Trauma
- Migration
- Discrimination / racism
- Spiritual causes
- Other psychological factors
- Family history
- Other
- Prefer not to answer

Specify:

### Your involvement in the care pathway

Are you aware of the team's current approach to supporting your loved one? \*

- Yes  No  Prefer not to answer

If yes, do you feel that you have been involved in the decisions regarding the goals/directions of the follow-up?\*

- Yes  No

Do you feel that your opinion has been taken into account by the team?\*

- Yes  No

Do you agree with the goals/directions of the work done by the team with your loved one?\*

- Yes  No

Comments:

Would you like to be involved in your loved one's care plan?\*

- Yes  No  Prefer not to answer

Are you aware of your loved one's diagnosis?\*

- Yes  No  Prefer not to answer

If yes, do you have a good understanding of the diagnosis?\*

- Yes  No

Explain:

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If no, is this a concern for you?\*

Yes  No

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Explain:

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### Your information needs

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Do you feel the need to know more about psychosis?\*

Yes  No  Prefer not to answer

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Can you identify the signs when your loved one is feeling worse?\*

Yes  No  Prefer not to answer

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If no, how would you like to be better equipped?\*

- Receive general information on the subject
  - Receive information from the team about your loved one's situation
  - Give information about your loved one to the team
  - Reassurance
  - Communicate your values, beliefs, opinions or concerns to your care team
  - I don't need to be better equipped
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Comments:

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If your loved one's condition deteriorates again, will you know how to manage the situation?\*

Yes  No  Don't know  Prefer not to answer

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Do you know what medications your loved one is taking?\*

Yes  No  My loved one does not take medication  Prefer not to answer

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Do you feel the need to know more about the care and services your loved one receives?\*

Yes  No  Prefer not to answer

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Does the fact that your loved one has to take medication worry you?\*

Yes  No  Prefer not to answer

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If yes, are you worried about your loved one going off his or her medication?\*

Yes  No

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Are you worried or concerned about the changes or side effects this is causing your loved one (now and in the future)?\*

Yes  No

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Are you worried about managing his medication?\*(  
e.g. going to the pharmacy or paying for medication)

Yes  No

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Would you like to add anything else about medication?

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If you wish to discuss your loved one's care with their healthcare team do you know who to reach out to?\*

Yes  No  Prefer not to answer

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If yes, are you comfortable communicating with members of the care team?\*

Yes  No

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Please specify:

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If no, would you like to know who to call?\*

Yes  No

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Do you feel the need to talk more with his care team?\*

Yes  No  Prefer not to answer

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If yes, on what subjects?\*

- To communicate information
  - For support
  - For general information
  - To obtain information about your loved one's situation (with his/her consent)
  - Other
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Please specify:

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Do you require any accommodations for your meetings with the team?\*(  
e.g: a language interpreter, virtual meeting, flexible hours, etc.)

Yes  No

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If yes, please specify:\*

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**Social and community support**

Are you receiving support within your community?\*(  
(for instance, through listening, counseling, or guidance)

- Yes
- No
- Prefer not to answer

If yes, from whom?\*

- Extended family
- Friends
- Employers/colleagues
- Religious leader
- Community organizations
- CLSC
- Other

Comments:

If no, what prevents you from using support resources?\*

Are you aware of the resources available in your community?\*

- Yes
- No
- Prefer not to answer

Can you identify someone you can confide in and discuss your loved one's illness or situation with?\*

- Yes
- No
- Prefer not to answer

Comments:

Are there elements of your identity or values that should be known and taken into account by his care team, in order to better support you as a loved one?\*(  
(sexual orientation, religion, ethnic origin, etc.)

- Yes
- No
- Prefer not to answer

If yes, please specify:

Does spirituality give meaning to your life or to this experience of illness?\*

- Yes
- No
- Prefer not to answer

If yes, does spirituality help you in life in general?\*

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Does your spirituality help you cope with your loved one's illness?\*

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When faced with a health problem, do you tend to use alternative and/or complementary approaches to medical treatment?\*

- Wellness practices (e.g. yoga, massage therapy)
- Traditional or alternative medicine (acupuncture, homeopathy, ayurveda, herbal medicine, etc).
- Spiritual practice (prayer, healer, shaman, etc).
- Let nature, the human body, solve the problem naturally
- Other
- None
- Prefer not to answer

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Please specify:

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Do you generally use these strategies?\*

- To replace standard medical treatments
- To complement standard medical treatments

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With the ordeal you are currently going through with your loved one, what is most important to you? \*  
You may choose up to 3.

- Getting closer to your loved one
- Improve communication with your loved one
- Better support for your loved one
- Helping your loved one to cope
- Striking a balance (work/family)
- Recharging your batteries (spending time with yourself)
- Other
- Prefer not to answer

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Please specify:

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Are there any other children or family members around you who have been affected by your loved one's health problem (directly or indirectly)?\*

- Yes
- No
- Prefer not to answer

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If yes, please specify

Do you feel the need to be supported by the care team to maintain a good relationship with your loved one? (e.g. mediation for treatment-related conflicts, dealing with illness symptoms that impact family dynamics)?\*

- Yes  No  Prefer not to answer

How do those around you react to the situation? \*  
You may choose up to 3.

- Solidarity
- Support
- Criticism
- Pressure
- Detachment
- Other
- Prefer not to answer

Specify:

Do you feel prepared to answer any questions your family or community members may have about your loved one's mental state and/or situation?\*

- Yes  No  Prefer not to answer

|   | Never                 | Rarely                | Sometimes             | Quite often           | Almost always         |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Are you hopeful that things will get better?* | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you ever feel discouraged or worried?*     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

### Your Support and Its Impact

The following 6 statements assess the burden you might feel as a caregiver. For each item, indicate how often you experience this situation in your relationship with the person you are caring for.

|  | Never                 | Rarely                | Sometimes             | Quite often           | Almost always         |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Feeling that the time spent with your loved one doesn't leave you enough time for yourself?*     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Feeling torn between the needs of your loved one and family or professional responsibilities?*   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Feeling that your loved one may be detrimental to your relationships with other family members?* | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Feeling tense in the presence of your loved one?*  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Feeling that your health has deteriorated because of your involvement with your loved one?\*

Feeling like you've lost control of your life since your loved one became ill?\*

Are you more than one person supporting your loved one?\*

Yes  No

|   | Never                 | Rarely                | Sometimes             | Quite often           | Almost always         |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you have the same understanding of the illness as the other people involved?*                                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you have the same level of involvement with your loved one as the other people involved?*                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you and the other involved individuals agree on the kind of support to provide and the boundaries to establish?* | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

**Safety**

|  | Never                 | Rarely                | Sometimes             | Quite often           | Almost always         |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Do you ever fear for your loved one's safety?*                                 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Have you ever felt concerned for your safety while being with your loved one?* | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Do you feel that the people around you are afraid of your loved one?*          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

In your opinion, to what extent should the care team take into account ..... when establishing your loved one's treatment plan?

|   | Never                 | Rarely                | Sometimes             | Quite often           | Almost always         |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| ... your values, your religion or your spiritual practices...*                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| ...alternative and complementary approaches to the usual medical approaches...* | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Do you have any other information to give us to help us take good care of you and your loved one?

## Transfer

As you know, follow-up care at the PPEP clinic has a limited duration. The end of your loved one's follow-up is approaching; it's likely the team has already begun planning a transfer to another care team (CLSC team, general psychiatric services in a hospital, family doctor, etc.).

Are you aware that this transfer to other services is coming soon?\*

Yes  No  Prefer not to answer

Are you worried about this team transfer?\*

Yes  No  Prefer not to answer

If yes, specify\*

Do you know which care team has been identified to take over the follow-up?\*

Yes  No  Prefer not to answer

Do you have any specific needs regarding this team transfer?\*

Yes  No  Prefer not to answer

If yes, specify\*

Are you aware of the resources available for your loved one or yourself for support from the community sector?\*

Yes  No  Prefer not to answer

## Personal characteristics

The diverse profiles of the young people receiving services at our clinic reflect the rich socio-cultural diversity of our Quebec community. Our team is committed to providing tailored, caring, and safe services for everyone.

If certain questions seem sensitive to you (for example, about economic situation or spirituality), please know that they are asked with the intention of meeting everyone's needs as effectively as possible with as few blind spots as possible. You are free to answer them or not. Again, this will not change the quality of care provided to your loved one or yourself.

As with the first part, your data will remain confidential.

If resources allow, what language of communication would you prefer for the services you receive from the treatment team?\*

French  
 English  
 Spanish  
 Other  
 Prefer not to answer

If other, please specify:

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What is your relationship with the person receiving services at the PPEP clinic?\*

I am their:

- Mother
- Father
- Partner/ spouse
- Brother or sister
- Grandparents
- Uncle or aunt
- Godfather or godmother
- Extended family
- Prefer not to answer

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What is your gender of identity?\*

- Female
- Male
- Non-binary
- Prefer not to answer

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What age group do you belong to?\*

- 10-20 years
- 21-30 years
- 31-40 years
- 41-50 years
- 51-60 years
- 61-70 years
- 71 and over
- Prefer not to answer

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What ethnic or cultural background do you identify with?\*

(Check all that apply)

- First Nations, Inuit, Métis
- Afro-descendant (African, Afro-Caribbean or Afro-Canadian ancestry)
- Latin American (Latin American, Hispanic ancestry)
- Middle Eastern (Arab, Persian, West Asian ancestry)
- East Asian (Chinese, Korean, Japanese, Taiwanese ancestry)
- South Asian (of Indo-Oriental, Pakistani, Sri Lankan or Indo-Caribbean descent)
- Southeast Asian (Filipino, Vietnamese, Cambodian, Thai, Indonesian, etc).
- Caucasian (European ancestry)
- Other
- Prefer not to answer

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If other, please specify:

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What religion or spiritual practice is important to you?\*

- Christianity
- Islam
- Judaism
- Buddhism
- Hinduism
- Sikhism
- Traditional spirituality
- Any other religion
- Any other spiritual practices
- No religious or spiritual affiliation
- Prefer not to answer

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Please specify:

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Have you experienced migration?\*

- Yes
- No
- Prefer not to answer

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If yes, what is your current immigration status?\*

- Canadian citizen or permanent resident
- Temporary resident (temporary worker, foreign student, visitor, etc).
- Asylum seeker
- Protected refugee
- I have no status in Canada or it is no longer valid
- Other
- Prefer not to answer

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If other, please specify:

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How would you describe your economic situation?\*

- Precarious (difficulty in meeting my family's basic needs on a regular basis)
- Sufficient to meet my family's basic needs (food, housing, etc).
- Somewhat comfortable
- At ease / Not an issue
- Other
- Prefer not to answer

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If other, please specify:

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