

STORIES OF CARE GUIDELINES

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Aim of the guidelines

These guidelines accompany the *StoriesOfCare* collection of family member stories and the corresponding Map of Topics, concerning family members who care for a person diagnosed with schizophrenia. The guidelines are intended to offer practical ideas for how the stories of care can be used as a resource across various settings and by different types of users.

The StoriesOfCare collection of family member stories includes caregiving stories from nine different caregiving constellations, reflecting diverse family perspectives on supporting a loved one with schizophrenia. These real-life narratives provide a rich basis for empathy-building, peer counselling, and professional training. The nine constellations of caregivers represented in the collection are:

- Mother caring for son (23 stories)
- Mother caring for daughter (14 stories)
- Father caring for son (10 stories)
- Sister caring for brother (6 stories)
- Daughter caring for mother (3 stories)
- Sister caring for sister (1 story)
- Brother caring for brother (1 story)
- Brother caring for sister (1 story)
- Wife caring for husband (1 story)

The Stories Of Care Map of Topics comprises **168 topics contained in 26 topic groups, which are organized into three thematic clusters.** The 26 topic groups reflect the major areas of experience of family members caring for a person diagnosed with schizophrenia. The first cluster, Cluster A, focuses on patient behaviour, symptoms, and disease course, containing 11 topic groups and 54 topics. It captures how family members experience symptoms such as hallucinations, delusions, suicidal behaviour, aggression, medication refusal, or repeated hospitalizations. Cluster B, with 6 topic groups and 45 topics, addresses the emotional experiences of family members, including feelings of helplessness, emotional exhaustion, guilt, uncertainty about how to behave in specific situations/ react to particular behaviours and symptoms of the sick family member, and the development of coping strategies. Cluster C encompasses specific contexts and systemic issues, comprising 9 topic groups and 69 individual topics. This includes practical and social challenges such as financial strain, family conflicts, difficulties with health and social care systems, lack of professional support, housing instability, legal issues, and experiences of stigma. Together, this system of topics offers a comprehensive lens to understand the diverse and often complex realities of caregiving and serves as a powerful guide for selecting and discussing stories in professional, educational, and support settings.

The guidelines outline four main areas of application (settings): 1) peer counselling; 2) family member peer-support groups; 3) professional education; and 4) public awareness. The guidelines include facilitation methods, discussion prompts, and ethical considerations to ensure stories are used respectfully and effectively.

Overview of settings, aims, and methods

Setting	Aim	Methods
1. Peer-counseling	Normalize overwhelming emotions, reduce feelings of isolation, and provide practical insight into how to cope with different situations	<ul style="list-style-type: none"> • Start by selecting narratives that align with the caregiver’s role (such as mother, sibling, or daughter) and the specific issues they are facing • Story can be read aloud or briefly summarized • Moderate the conversation with open-ended questions such as: “Does anything in this story feel familiar to you?”
2. Family member peer-support groups)	Use storytelling to stimulate discussion and empathy among participants of family member groups	<ul style="list-style-type: none"> • Start sessions with a family member’s story • Facilitate group reflection on the story’s themes • Encourage participants to share their own experiences
3. Professional Education	Integrate real-life stories as teaching tools for healthcare professionals to add a real-life perspective to professionally codified knowledge as contained in textbooks	<ul style="list-style-type: none"> • Introduce stories as case studies • Use stories in simulation exercises • Assign reflective writing • Discuss the impact of mental illness on families and how the professional can reduce this impact by providing timely information and support
4. Public Awareness	Use personal stories to humanize mental health issues and reduce stigma.	<ul style="list-style-type: none"> • Feature stories in awareness campaigns. • Share excerpts in infographics and on social media. • Host community events with story readings. • Collaborate with local media for interviews.



Guidelines for using the stories in counselling sessions offered by family members' associations

The StoriesOfCare narratives can serve as powerful tools in both one-on-one and group counselling sessions led by peer counsellors within family associations. These real-life stories help normalize overwhelming emotions, reduce feelings of isolation, and provide practical insight into how others have coped with similar situations. The primary purpose of using these stories is to support family members in distress by offering emotional validation, connection, and hope through shared lived experiences.

To use the stories effectively, counsellors should begin by selecting narratives that align with the caregiver's role—such as mother, sibling, or daughter—and the specific issues they are facing, such as suicidal threats, financial difficulties, or hopelessness. The Map of Topics can assist in making targeted selections. Introduce the story as a real-life account, emphasizing that others have faced and navigated similar struggles. The story can be read aloud or briefly summarized, creating space for emotional reaction and personal reflection. Counsellors can then guide the conversation with open-ended questions such as: “Does anything in this story feel familiar to you?”, “What part of the story stood out or moved you?”, or “How do you relate to this caregiver's experience?” This approach helps foster empathy, validation, and a sense of shared understanding.

Guidelines for using the stories in group activities

Many family members feel isolated, believing their struggles with fear, unpredictability, and guilt are unique. These guidelines provide a structured approach for facilitating group sessions where participants in family member peer-support groups use narratives from the StoriesOfCare Collection to foster empathy, appreciation, and connection. Reading and discussing a story like this provides immediate recognition and appreciation in the following ways:

- **Recognition of Common Struggles:** The stories directly address core themes relevant to family members, such as the tension between wanting to help and needing a break, the fear of hospitalization, and the pain of witnessing a loved one's withdrawal.
- **Learning by example from other families:** Family members often serve as powerful role models in times of stress or transition. Observing how others cope with challenges such as illness, disability, unemployment, or caregiving can offer practical strategies, emotional strength, and reassurance. This shared experience builds resilience and helps normalize difficulties.
- **Exchanging practical information:** Families can be valuable sources of informal knowledge. Members often share insights and experiences on medication management (e.g., side effects, scheduling, dosage tips); navigating social services (e.g., applying for benefits, housing support) or accessing healthcare and community resources (e.g., local clinics, mental health services). This peer-to-peer knowledge exchange can complement professional advice and fill in gaps in formal support systems.

- Reducing Isolation: Hearing their own emotions articulated through someone else's story can reduce feelings of loneliness and normalize complex emotions like anger and despair.
- Fostering Empathy: By discussing the story, participants can move beyond their situations to develop empathy for other family members, understanding that their fears and burdens are shared.
- Creating hope and arriving at „positive resignation“: Seeing in the stories how other families coped with the difficult situations can inspire family members to find solutions for their challenges.

Purpose: To create a supportive environment where family members can explore emotions, recognize shared challenges, and gain appreciation through the discussion of shared narratives from the StoriesOfCare Collection.

Objectives:

- Facilitate group reflection on complex themes related to caregiving and family dynamics.
- Encourage participants to share personal experiences in a supportive setting.
- Utilize StoriesOfCare narratives as illustrative examples for specific themes or as conversation starters when participants are hesitant to volunteer topics.

Preparation:

1. Select a story; choose a narrative from the StoriesOfCare Collection that resonates with the group's experiences and encapsulates specific themes for discussion.
2. Familiarize yourself with the narrative; understand the story's context, emotional arc, and potential discussion points.
3. Prepare discussion prompts; develop open-ended questions tailored to the story.
4. Secure the environment; ensure the setting is comfortable, confidential, and conducive to open communication.

Step-by-Step Facilitation Guide:

1. Introduction and story presentation

Greet the group and clearly state the session's focus: exploring empathy through the StoriesOfCare narrative. Remind participants that all shared information remains within the group. And then deliver the chosen narrative from the StoriesOfCare Collection sensitively.

2. Guided reflection and thematic discussion

Start broadly to help participants ease into the conversation. Focus on the narrative itself before moving to personal feelings.

- "What was your immediate reaction to this story?"

- "What specific themes or feelings stood out to you in this narrative?"
- "Were there any moments or phrases in the story that particularly resonated with you?"

3. Connecting and sharing experiences

Gradually transition the conversation to personal experiences, using the story as a bridge. Encourage participants to relate the story's themes to their own lives. Remind participants to listen empathetically without judgment and acknowledge the emotional courage of those who share. Frame personal stories as valuable contributions that reduce isolation and normalize struggles. You can ask: "How does this story compare to similar situations you have witnessed or experienced?"

4. Facilitating discussion with family members

When facilitating this activity with a group of family members, it is crucial to create a safe and non-judgmental environment.

- Acknowledge the intensity of the themes; participants may react strongly, as the stories touch on deep-seated fears.
- Focus on feelings, not solutions; remind the group that the purpose is to share and understand, not to provide advice or solve the dilemmas presented in the story.
- Voluntary sharing; emphasize that participants only share what they are comfortable with. The story itself provides enough material for a meaningful discussion, even if participants choose not to share personal experiences.

Guidelines for using the stories in the professional education of medical doctors, nurses, psychologists, and social workers

To provide the best possible care to an adult living with mental illness while sustaining their well-being, family members usually need:

- to know that their relative is receiving appropriate care and has access to the services and supports that will maximize their potential for quality of life.
- to have their relationships and caregiving roles recognized by mental health service providers and to be meaningfully involved in assessment and treatment planning.
- to receive information and timely support from knowledgeable mental health service providers, including in enhancing their coping skills, so they can effectively provide care to their relative.
- to have their personal needs outside of their caregiving role recognized and supported to sustain their own health and emotional well-being.

These guidelines detail the use of real-life narratives from the StoriesOfCare Collection as teaching tools for professionals, including medical doctors, nurses, psychologists, and social workers.

Purpose: to sensitise professionals to the problems of the family members by integrating real-life stories as teaching tools for healthcare professionals.

Methods: The guidelines outline three methods for achieving this:

Method	Description	Goal
Case Studies	Use real stories as case studies in teaching sessions.	Sensitize professionals to family issues.
Simulation Exercises	Role-play scenarios based on narratives to practice communication and support skills.	Improve provider-family interactions.
Reflective Writing	Assign writing tasks focused on family experiences and responses to narratives.	Foster empathy and self-awareness.

Training professionals using the case stories of family members of people with schizophrenia is a highly effective approach for increasing empathy, understanding, and practical skills among clinicians, social workers, nurses, psychologists, and law enforcement officers. Here’s how and why this method works, based on current evidence and best practices.

Firstly, real-life family stories provide context-rich, relatable scenarios that illustrate the emotional, social, and practical challenges families face when supporting someone with schizophrenia. These stories help professionals move beyond textbook knowledge, exposing them to the lived realities of caregiving, such as stigma, isolation, crisis management, and the ongoing burden of care.

Secondly, case studies highlight how schizophrenia affects the entire family system, not just the individual with the diagnosis. They reveal the impact on family relationships, communication, and the mental health of caregivers. By analyzing these stories, trainees can identify common problems (e.g., managing crises, navigating healthcare systems, dealing with societal stigma) and recognize the strengths and resilience families display. This approach fosters empathy and reduces negative stereotypes or assumptions professionals might hold about families of people with schizophrenia.

Training sessions can include structured case discussions, role-playing, and problem-solving exercises based on real family experiences. Through these, professionals learn to:

- Recognize and address the emotional needs of family members.
- Communicate effectively and empathetically with families.
- Provide psychoeducation, crisis intervention, and support for coping strategies.
- Understand the importance of involving families in treatment planning and relapse prevention.



Having a map to link topics to the stories ensures the rapid selection of stories for different types of learning contexts or topics.

Guidelines for using stories for public awareness

Personal stories from family members of people living with schizophrenia are powerful tools to help the public better understand this complex condition. These stories humanize the experience, break down misconceptions, and foster empathy. Here are effective ways to share and amplify these voices:

1. Feature family stories in awareness campaigns

Highlighting the journeys of families affected by schizophrenia in public campaigns helps bring the condition into everyday conversation. These stories reveal the realities behind the diagnosis: the challenges, the hope, and the strength families demonstrate. The stories of mothers, fathers, sisters, or brothers from our collection at storiesofcare.eu bring to life the emotional journey and resilience of families, making the impact of schizophrenia more relatable for the general public

2. Share excerpts on social media and in infographics

Short, meaningful quotes or moments from the storiesofcare.eu collection of family stories can be shared on social media platforms or included in visually engaging infographics. This approach reaches a broad audience and encourages others to engage in conversations about schizophrenia. Pairing stories with educational facts helps dispel myths and provides helpful resources.

3. Host community events featuring family story readings

Community events such as story-sharing evenings or panels where stories can be read create safe spaces for connection and understanding. These gatherings help reduce feelings of isolation for families and encourage a supportive community dialogue.

4. Collaborate with local media for interviews

Local newspapers, radio shows, and TV programs provide valuable platforms for family members to share their stories. These interviews help educate the wider community, challenge stereotypes, and highlight the importance of support systems for people living with schizophrenia. However, sharing is often difficult, and the voice of a family member is underrepresented in the public discourse. Our storiesofcare.eu collection offers a resource for such situations and can be used to highlight the challenges that family members might be facing.