



Schizophrenia®
& Psychosis
Action Alliance

I'm Diagnosed. Now What?

A toolkit for navigating
the schizophrenia journey

PART TWO: ACHIEVING STABILITY

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Introduction

This document was created with you in mind, offering tips and strategies specifically for those diagnosed and seeking guidance and support.

Once you have been diagnosed with schizophrenia or a related disorder, started a treatment plan and begun to educate yourself about the disease, you can start to rebuild a life of purpose and meaning. This can include returning to past hobbies or finding new ones you enjoy, volunteering and learning how to establish and work with your support system. This toolkit section helps guide you on your path to achieving and maintaining stability.

“Recovery is a process of change through which individuals improve their health and wellness, live self-directed lives and strive to reach their full potential.”

- SAMHSA’s Wellness Guide defining recovery and its dimensions



Find Purpose and Meaning

Exploring life beyond diagnosis.

Discovering and nurturing your strengths and interests can help you find purpose, hope and fulfillment. Here are some ideas to get started.

Explore your hobbies

Engaging in hobbies can be a wonderful way to take smaller, manageable steps toward staying active and finding meaning during your recovery journey. Starting with hobbies allows you to explore your interests and passions without the pressure of larger commitments.

Whether you choose to write, paint, knit, garden, listen to music or play a sport, these activities can help you channel your emotions and find a sense of peace. Hobbies also often provide opportunities to connect with others who share your interests, fostering a sense of community and reducing feelings of isolation. Joining a local club, taking a class or participating in online forums can open doors to new friendships and support systems. By immersing yourself in activities you love, you not only nurture your creative side, but also give yourself the time to heal and grow in a supportive, low-pressure environment.


As you gain more comfort and enjoyment from these hobbies, you may find yourself ready to take the next step into the more structured and social aspects of volunteering. By gradually increasing your involvement in meaningful activities, you'll create a solid foundation that supports your wellbeing and prepares you for more significant commitments.





Build confidence with volunteering

Volunteering can be an important step toward professional recovery and gradually returning to work. Try the approach below to help you build confidence, improve your social skills and create a routine that can prepare you for the structure of eventual work:

- 
1. Start by identifying areas of interest and causes that resonate with you.
 2. Look for volunteer opportunities that align with your strengths, such as at local mental health organizations, community centers or other nonprofits such as S&PAA.
 3. Begin with small, manageable commitments, such as a few hours a week, to help you adjust.
 4. Many organizations have opportunities to volunteer virtually as well as in person. Either can work, depending on what's most comfortable for you and your needs.

As you become more comfortable and confident in a volunteer role, consider increasing your responsibilities or the number of hours you contribute. Many people start with 5-10 hours per week, then build from there. Keep track of how you feel after each session and adjust your schedule accordingly. Ensure you maintain a balance between volunteering and self-care, incorporating relaxation techniques, hobbies and social activities into your routine.

This gradual progression can help you develop a sense of purpose and improve your time-management skills. Engaging in tasks that use your strengths and interests also can provide valuable experience that you can transfer to a professional setting. Remember: the goal is to build a sustainable routine that supports your mental health while allowing you to grow and learn in a supportive environment.

Build work opportunities from volunteering

Many people who live with schizophrenia eventually find their way back into meaningful work and purposeful recovery. Transitioning from volunteering to gaining professional experience and eventually returning to work is a significant step in your recovery journey.

It's important to acknowledge your accomplishments as a volunteer and consider how they have prepared you for a paid work position:

- **Start by identifying the skills you've developed.** These might include teamwork, communication, problem-solving and time management. Recognizing these abilities can boost your confidence and help you see the value you bring to a professional setting.
- **Next, consider how to gradually integrate professional experiences into your routine.** Look for part-time or flexible job opportunities that align with your interests and skills. Starting with roles that are similar to your volunteer work might be helpful. Reach out to organizations you've volunteered with to explore potential job openings or ask for recommendations. Networking with professionals in your field also can provide valuable insights and opportunities. Remember to communicate your needs and boundaries to your employer to help ensure a supportive and accommodating work environment as described in **NAMI's guide**.

Returning to work can be both exciting and challenging, so it's crucial to maintain balance. Your wellbeing is the most important, so remember to take things at your own pace.



“I needed to put two critical ideas together: that I could both be mentally ill and lead a rich and satisfying life.”

— Elyn R. Saks, **“The Center Cannot Hold: My Journey Through Madness”**

Future building: Strengths and interests



Embarking on your recovery journey is a deeply personal and empowering process. One of the most important steps you can take is to identify and build on your strengths and interests to help you navigate challenges and find fulfillment. Whether it's a talent for music, a knack for problem-solving or an ability to connect with others, recognizing and nurturing these strengths can provide a solid foundation for your recovery.

You can use the following worksheets to help identify your strengths and interests as well as areas that would be worked on. This space is for you to put these ideas on paper and think through your own strengths and interests in a practical way beyond just abstract ideas.

List your strengths & interests. You can use these categories to get started!

Personal Skills: Share some examples of these skills and possible ways you could build on them:

Problem solving: _____

Creativity: _____

Resilience: _____

Empathy: _____

Communication: _____

Other: _____

Hobbies: What do you enjoy? What supports your wellbeing?

Arts and crafts: _____

Music (listening, performing): _____

Sports and physical activities: _____

Reading and writing: _____

Gardening: _____

Other: _____

Social Strengths: List any examples or work in progress:

Supportive relationships: _____

Family involvement: _____

Peer support: _____

Community connections: _____

Other: _____

Social Interests: What more can you do in this area?

Preferred social activities: _____

Group/Community memberships: _____

Event participation: _____

Other: _____



Describe your education & experience. You can use these categories to get started!

Education – what have you accomplished and what could you work on?

Subjects of interest: _____

Desired courses or certifications: _____

Learning style (visual, auditory, hands on): _____

Past accomplishments: _____

Other: _____

Academic/Professional strengths:

Educational background: _____

Work experience: _____

Skills and certifications: _____

Other: _____

Vocational interests: _____

Preferred job or career roles: _____

Volunteer opportunities: _____

Long-term career goals: _____

Other: _____



List your daily life & wellness skills. You can use these categories to get started!

These things may seem difficult to manage now, but they can be built and re-learned over time with the right treatment team and support. Be sure to tap into your treatment and support team for help.

Managing your life and wellness through these skills has been possible for many with a similar diagnosis and journey. Slow and steady wins the race!

Daily living skills: _____

Regular daily schedule: _____

Personal hygiene: _____

Cooking skills: _____

Financial management: _____

Time management: _____

Other: _____

Establishing consistent habits around activities you enjoy helps develop your skills, restore a sense of normalcy, manage your symptoms and foster a sense of control and achievement.

Set Yourself Up for Success

Remembering to take your medications

Taking your medication consistently can feel challenging, but there are simple strategies to help.

- Consider including your medication as part of a daily routine, such as brushing your teeth or eating breakfast. This makes taking your meds a natural part of your day.
- Set reminders on your phone or use a medication management app to prompt you when it's time to take your medicine.
- Use visual aids, such as sticky notes or calendar entries.
- Keep a pill organizer to help you track your doses and ensure you don't miss any. Many organizers have colorful tabs labeled with the days of the week. Some are electronic and can sync with your smartphone to remind you to take your medication.

And don't forget to reward yourself for sticking to your routine, whether it's with a small treat or some relaxing downtime. Each time you take your medication, you're taking an important step toward stabilization and recovery.

“I am bent, but not broken. I am scarred, but not disfigured. I am sad, but not hopeless. I am tired, but not powerless. I am angry, but not bitter. I am depressed, but not giving up.”

— Anonymous





Housing

Depending on your family situation, you may need to seek your own housing. This may involve seeking assistance through your state or county. Because states and counties often approach supported housing differently, there is no single best approach to finding it.

To get you started, following are some options to explore:

- **Behavioral Health Case Management** can help you identify the housing that is most appropriate for your needs and provide you with the wrap-around support necessary to maintain that level of housing. This can be found through Medicaid or your state health department.
- **Your state's department or division of mental health.** For example, in Massachusetts, the name of the agency is the Massachusetts Department of Mental Health.
- **Section 811 Supportive Housing** integrates affordable housing with access to mental health services to provide stability, with some support specific to being disabled. Some programs require a person to assign someone to be their “representative payee,” who would be in charge of ensuring the rent is paid.
- **The U.S. Department of Housing and Urban Development (HUD)'s housing locator** funds some independent living apartments with varying levels of support. Group homes and residential treatment facilities offer a structured environment with around-the-clock care and supervision.
- **The Directory of Centers for Independent Living** provides a detailed list of consumer-controlled, community-based, cross-disability nonprofit agencies that are designed and operated by people with disabilities and provide an array of independent living services.
- **The Housing Choice Voucher Program (Section 8)** helps people afford private rental housing. This program can have a waitlist of months or years, so consider applying for bridge housing **subsidies** in the meantime.
- **Your local Public Housing Agency (PHA)** can provide referrals for subsidies, guidance for Section 8 voucher holders and help residents of public housing in general.
- **The Homeless Shelters Directory** can help you access immediate housing support and other social services throughout the United States.

Local mental health agencies also may be able to connect you with suitable housing resources and provide ongoing support to maintain your housing stability.

Disability services

Navigating the maze of disability services can be challenging, but with persistence and the right resources, you can secure the support you need. Disability services can include disability income, healthcare, education, employment assistance and daily living support, which help people access opportunities and live more independently. A person with schizophrenia may qualify for these services if they have documented evidence of a condition that significantly limits daily activities, meet specific eligibility criteria and demonstrate a need for support.

Your family members or other loved ones can help you complete and process your Social Security Disability application, which is a part of getting access to disability services.

- Begin by organizing your medical records, including detailed reports from your healthcare providers that outline your diagnosis and treatment history. These documents are essential for proving your eligibility and will help make the application process smoother. Don't be afraid to advocate for yourself by asking your healthcare providers for detailed reports and recommendations about what to consider when thinking about applying for disability.
- Once you have your medical records, a local disability services office or its website can help you understand the specific disability requirements and procedures in your area. Many offices have staff who can provide initial consultations and help you understand the process. The **USAGov** website also can help you find affordable legal support from lawyers who specialize in Social Security Disability applications – see also the **National Disability Rights Network**.

Mental health organizations and advocacy groups such as **SAMHSA's SOAR program** also can provide resources and support. Stay determined and remember that every step you take brings you closer to getting the support you deserve.

You also may want to explore obtaining:

- **Social Security Disability Income (SSDI):** Monthly benefits for people who have a medically determinable disability that restricts their ability to be employed. Benefits are based on the disability and type of previous employment.
- **Supplemental Security Income (SSI):** Similar to SSDI, but eligibility is based on your age, disability and income.
- **Medicaid:** The federal/state public health insurance program for people with low incomes.
- **Medicare:** The U.S. federal health insurance program for people age 65 or older and younger people with disabilities.
- **Supplemental Nutrition Assistance Program (SNAP):** A federal program that provides food-purchasing assistance for people with low or no income.
- **Travel reimbursement options:** Social Security offers these in some cases to cover transportation expenses as well as unusual costs due to special circumstances.
- **In-home care services:** Services with help for daily activities, including personal care, giving medicine, cooking and cleaning.

Preparing for a possible hospitalization

Facing the possibility of hospitalization can be daunting, but taking steps to prepare for it can help you feel more secure and in control.



1. Begin by assembling a personal crisis plan (see Part 3 of this toolkit) that details your medical history, current medications and emergency contacts. Share this plan with trusted friends, family members and your healthcare providers so they can support you effectively during a crisis.



2. Pack a small “go bag” with essentials such as comfortable clothing, toiletries and personal items that bring you comfort.



3. Familiarize yourself with local hospitals and mental health facilities. Research their services and choose a facility that aligns with your needs and preferences. Contact these facilities to learn about their admission procedures and what to expect during a stay.

This process can ease your uncertainty about a potential hospitalization and reduce the stress caused by a sudden need to be hospitalized.

Your preparation also should include knowing your local crisis line phone number. If there isn't a local resource, keep the **988 Suicide & Crisis Lifeline** handy. It provides 24/7 access to phone, text and chat options with trained crisis counselors. These counselors can help you if you are experiencing suicidal thoughts or other mental health crisis, substance use or any other type of emotional distress.





How to Talk with Your Support System

Talking with family, friends and loved ones

Effective communication with the people closest to you is crucial to help navigate the early warning signs of a crisis. Remember, it's OK to ask for help and lean on others during these times. Here are some pointers and example statements on how to approach these conversations:

Express your feelings clearly:

- “I've been feeling more overwhelmed and anxious than usual, and I'm starting to worry about my symptoms worsening. Can we talk about what I'm experiencing?”
- “I feel like _____ symptoms are getting harder to manage. Can we talk through how I could better manage them?”
- Practice stating how you feel using “I” statements, such as “I feel,” “I think” or “I need,” to express yourself directly and clearly.

Keep a daily log of your feelings and symptoms. This can provide you and others with more concrete information and help you track changes over time.

Ask for specific support:

- “I could really use your help monitoring my symptoms more closely this week. Can you check in with me daily to see how I'm doing?”
- “I've noticed that I'm starting to hear voices more frequently. Could we set up a plan to help me stay grounded when this happens?”
- “I've been having more trouble concentrating and my thoughts are becoming jumbled. Can you help me keep track of my symptoms and remind me to take my medication?”
- “Please let me know if you notice changes in my behavior that I might not see. It's important for me to address these signs early.”

Be clear about what type of support would be most helpful to you, whether it's emotional, practical or something else.

Communicate your needs calmly:

- “Lately, I've been having a harder time managing my thoughts and emotions. It would help me a lot if we could create a calm environment at home.”
- “I'm struggling to manage my day-to-day tasks. Can you help me with grocery shopping or household chores until I feel more stable?”

Try to discuss your needs during a calm moment, rather than waiting until you feel overwhelmed or are in crisis. Use calming techniques such as deep breathing or mindfulness before conversations to help maintain a peaceful tone.

Request assistance for appointments:

- “I think it might be time for me to see my doctor or therapist again. Can you help me make an appointment and come with me for support?”

Keep a list of questions or topics to discuss with your healthcare provider to make the most of the visit. Schedule regular check-ins with your provider, even during periods of stability, to maintain a strong support system.

Seek understanding and patience:

- “I'm noticing some early signs that worry me, like hearing things others don't. Please be patient with me as I navigate these feelings.”
- “Can you help me understand what you're seeing when my symptoms flare up, so we can work together to manage them?”

Educate your close trusted contacts about your schizophrenia symptoms and what early warning signs of a crisis might look like. Remind them that recovery is a journey, with ups and downs, and that their patience can make a positive difference.

Educate about your triggers:

- “I've noticed that certain situations are triggering my symptoms more than before. Let's discuss what those triggers might be so we can avoid or manage them better together.”

To help identify triggers, think about past experiences when you've had severe symptoms. Involve your support system in your coping strategies, so they can help reinforce positive behaviors and environments.

Plan for crisis together:

- “Let's update our crisis plan together in case my symptoms escalate. Having a plan in place makes me feel safer and more prepared.”
- “Could you please help me review my medical information and history to make sure everything is up to date, just in case? I want to make sure we are proactive about keeping me as healthy as possible.”

Regularly review and adjust your crisis plan as your needs and circumstances change. Include important contact information, medication details, mobile crisis unit numbers, hospital numbers and preferences for care and share copies with those you trust.

Talking with your healthcare providers

Understanding your condition, treatment options and the support available to you is essential. When you meet with your healthcare provider, come prepared with questions that can help you gain clarity and make proactive, informed decisions about your care.

You can use the worksheet below to take notes during provider appointments:

Understanding your diagnosis

Can you explain my specific type of schizophrenia and what symptoms have led to this diagnosis?

How does my specific diagnosis differ from other diseases that may be similar/have similar symptoms?

How can I tell if my symptoms are getting worse, and what should I do if they are?

Medication and treatment options

What medications are recommended for my condition, and how do they work?

What is the difference between a long-acting injectable vs. an oral pill for this medication?

Are there potential side effects from the medications I should be aware of?

What types of check-ups should I get (and how often) to monitor the medicine's effectiveness?

Therapy and other support

What type of therapy do you think will be most beneficial for me?

Can you recommend a provider who specializes in my diagnosis?

Can you recommend any local support groups or community resources for people with schizophrenia-related disorders?

Are there peer support programs available?

Future planning

What local resources should I seek if I experience a crisis?

Are there accommodations or support services I should consider seeking at my workplace or school?

Are there any services available at this facility to help me plan my future while managing my schizophrenia?

Lifestyle and wellness

Are there lifestyle changes or habits that can help manage my symptoms?

How important are diet, exercise and sleep in my treatment plan?

Communication and relationships

How do I explain my diagnosis to my family and friends?

What are the most important things my family and friends need to know about my disease?

Schizophrenia Resource Line & Support Groups



S&PAA offers a Resource Line and several support groups for people with schizophrenia/related disorders and family members of those with the disease. See **Part 1** of this toolkit for details about our Resource Line, support groups and other online resources.

**Shattering barriers to treatment,
survival and recovery for people
with schizophrenia and other
psychosis spectrum disorders.**

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