



THE
UNSTOPPABLE CAREGIVER

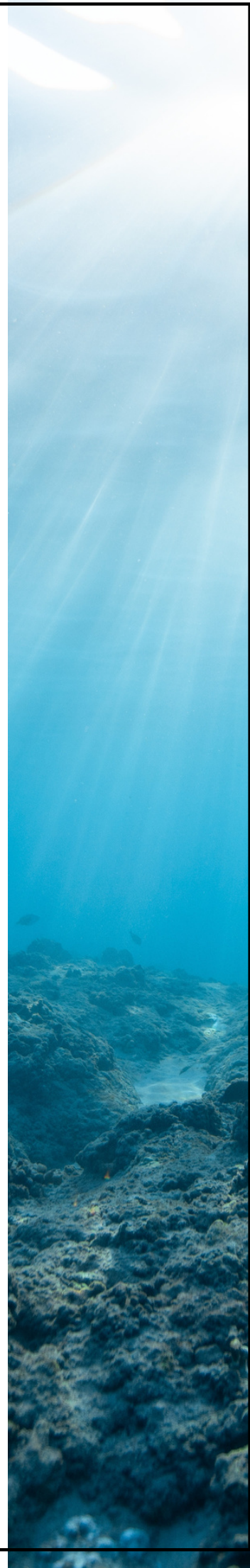
of
Loved Ones
with
SCHIZOPHRENIA SPECTRUM
DISORDERS

A Practical Action Guide

juanitawaltoncoaching.com

TABLE *of* CONTENTS

Introduction	page 3
Action 01 Create a Self Care Plan	page 5
Action 02 Create a Documentation Binder	page 7
Action 03 Educate Yourself	page 10
Action 04 Learn to Communicate Differently	page 12
Action 05 The Mental Health Act	page 14
Action 06 Legal Authority	page 15
Action 07 Help Agencies	page 17
Action 08 Government Benefit Programs	page 19
Action 09 Build a Care Team	page 21
Action 10 Streamline Your Life	page 23
A Final Word	page 25
P.S. Find Your People	page 26
juanitawaltoncoaching.com	



INTRODUCTION

Greetings fellow Caregiver,

So, you've suddenly become the caregiver of a loved one who has been diagnosed with a Schizophrenia Spectrum Disorder.

Once you get over the shock and have a chance to sit back and breathe a little, you're probably asking yourself, what do I do now? Where do I even start?

I was in the same position many years ago, after my daughter was diagnosed at age 19. I struggled trying find information that would help me put all the pieces together in any kind of sense. As a caregiver, I wasn't offered the support I knew I needed, so I was forced to go searching for it myself.

As you have already discovered, support varies depending on where you live, and even then, you are often left to figure things out for yourself.

Luckily, I'm a researcher kind of person, so I knew how to start digging. And this helped me to figure out what to focus on.

I've put this practical guide together to help you get your head around what you need to know and do. I wish someone had handed this to me when I was starting out. I hope this helps you get a handle on things.

But first, before you get started, always remember to be kind to yourself. Caring for someone with Schizophrenia Spectrum Disorder is a BIG learning curve, and you don't need to rush things. It takes months to process and navigate your way around your loved one's illness and your role in their care.

Nevertheless, if you follow this guide, you will regain control of your life and your situation. It may not be perfect; it'll always be the 'new normal', but even if you do one thing, it will make a big difference.

So, take one action step at a time consistently, and before you know it, you'll become an expert in your loved one's care.



Best regards,

Juanita Walton



01. CREATE A SELF CARE PLAN

This is a self care plan for YOU. You are that important.

Self care is not what happens after your loved one is cared for; self care comes first, before everyone else. I know you're going to feel guilty taking time for yourself, but you are not being selfish; it is essential that you take care of yourself. How else can you thrive while caring for your loved one?

The reality is, if you do not take care of yourself, you run the risk of burning out and developing depression, which is not a fun place to be, and it renders you incapable of giving the best care possible to your loved one.

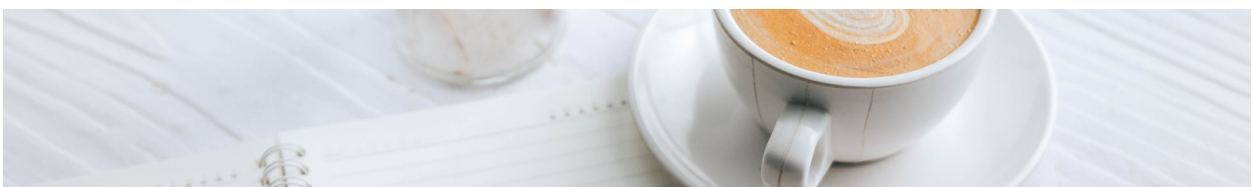
Self care ranges from the small moments we carve out in the day, like when we stop to watch a hummingbird, to arranging for someone to cover for you while you get groceries, to going away on a trip by yourself or with a friend. The possibilities are endless and only you know what you need and what feeds your soul.

One of my self care rituals is having my first cup of coffee in the early morning when the house is quiet and still. I sit and look outside as the world wakes up. This simple ritual sets me up for the day. I highly recommend you create your own special ritual that feeds your soul.

Don't put this off! Create a list of what matters to you and which activities feed you. Follow through on your list as often as possible, and as soon as possible.

Self care plans could include, but are not limited to:

- Talking to a psychologist – you need to process this journey with a professional
- Hiring a Life Coach to help you with finding practical solutions
- Finding or creating a support group of people going through the same thing
- Learning to practice Mindfulness as a tool for de-stressing
- Me-time rituals
- Weekly scheduled date time with yourself
- Small breaks during the day
- Spending time with friends
- Meditation or quiet time
- Daily movement that you love to do – dance, yoga, walking or sports
- Good nutrition
- Indulging in a hobby
- Fun activities
- Mini vacations (field trips)
- Learning to say no to activities you don't want to do
- Anything else that you love to do





02. CREATE A DOCUMENTATION BINDER

What is a Documentation Binder?

It's critical that you document EVERYTHING, whether it is the behaviour of your loved one, what is said at appointments, or anything else that seems important because you are going to become the expert of your loved one.

You are their 'brain by proxy' and this Documentation Binder will help you:

- Make important decisions about their care
- Understand your loved one better
- Have evidence for medical matters
- Have evidence for legal matters
- Present as an authority over your loved one, in front of medical or legal people
- Ease your mind by having everything in this binder, rather than scattered about in your brain or somewhere in your house

Go out and get a binder, some paper, and create the following sections to help you keep track of everything. Here are the section headings you need (LABEL them):

1. Daily Notes

Every evening, under today's date, briefly write down your loved one's behaviour today.

Notes that matter:

- good day/bad day
- activities that day
- sleeping patterns
- eating patterns
- medication side effects
- agitations
- anything unusual
- anything else you wonder about
- notes about today's appointments

2. Medical Treatments

- Have a printout of the current treatment plan.
- Include medications and dosage.
- Include a printout of possible side effects of medications.
- If the treatment plan changes, DO NOT throw out old plans. Keep these in the binder so that you have a history of all treatments and side effects. Just place the new plan on top of the old ones.
- Make sure everything is DATED.



3. Medical Team

- Names, addresses of clinics and phone numbers.
- This is good to have if you ever need anyone else to take your loved one to appointments or if you need to inform anyone else who needs to know.
- Again, keep old information underneath the new, because sometimes you will need the history.

4. Guardianship, Conservatorship, Power of Attorney, etc.

- Place all legal documents here pertaining to your legal authority over your loved one, if you have it or are attempting to have it.

5. Government Benefits

- Place all documents pertaining to any financial benefits your loved one gets from government sources.

6. Legal Matters

- Place all documents pertaining to legal matters your loved one is involved in, whether it be with the police, lawyers, or the courts.

7. Mental Health Act

- Find and print out the Mental Health Act in your jurisdiction.
- Read it.
- Study it.
- Become an expert so that you are able to talk about it with authority to the doctors and the police.





EDUCATE YOURSELF ABOUT

03. SCHIZOPHRENIA SPECTRUM DISORDERS

Learn everything you can about Schizophrenia Spectrum Disorders.

Create a file of information (paper or digitally) so that you can discuss this illness with anyone who comes into contact with your loved one's care. You have become your loved one's advocate, and you need to know as much as you can so that you make the proper decisions for them. You will find that general physicians don't know a lot about this illness, so make sure you can speak up and provide proper information when needed.

You need to know:

- The spectrum – from schizophrenia, schizoaffective disorder to bipolar, and everything in between.
- What psychosis really is.
- Anosognosia – what it is and how important this symptom is
- All the negative symptoms – and what that means.
- All the positive symptoms – and what that means.
- Treatment options and their side effects.

Once you have done your research, you'll be able to discern what's going on with your loved one. Every person exhibits their own version of this illness, and every person responds to treatment options differently. Every brain is different, so there is no predicting how your loved one's brain will respond, so learn as much as you can.

Stay current:

- Over time, more research is conducted; theories change and treatments improve so have a practice of reading medical articles about ongoing research.
- Start your research with local agencies in your area that will have some basic information.
- Expand your research with scholarly articles about ongoing research.





04. LEARN TO COMMUNICATE DIFFERENTLY

Anosognosia.

This is the major symptom of this spectrum that causes the most problems. Essentially, the part of the brain that tells your loved one they are sick is damaged. Your loved one does not know they are sick, which is why they refuse or resist treatment. This is incredibly confusing to them when people are insisting they get help.

Your loved one is not being stubborn or in denial. They literally do not know they are sick.

This happens to people with Schizophrenia Spectrum Disorders, dementia and Alzheimer's.

For your loved one, it is possible that with treatment they will regain the ability to know they are sick. This is called having 'insight', which I think is a weird way of putting it, but regardless, you hope your loved one regains the knowledge their brain is sick.

My daughter now knows she has Schizophrenia and is okay to tell people about it, but this only came after a long period of involuntary treatment.

When your loved one doesn't have 'insight', you need to find a new way of talking to them especially when they are delusional. A communication style that honours who they are and doesn't treat them as if they are a stubborn child.

You cannot rationalize with someone who is irrational because there is no logical argument to be made if the brain cannot be logical. You cannot win. A delusional argument only ends in frustration and hurt feelings. Your journey together will be fraught with so much stress already.

So, what to do?

I cannot stress enough that you absolutely need to:

- Read the book: *I Am Not Sick I Don't Need Help* by Xavier Amador.
- Watch Dr. Amador's videos.
- Learn the **LEAP** way of communicating. It will change everything!
- <https://leapinstitute.org/about-dr-amador/>

As a side effect, you might find that all your relationships improve when you adopt the LEAP way of communicating, because it teaches you about what matters when communicating with anyone.





05. READ THE MENTAL HEALTH ACT IN YOUR JURISDICTION

Read and understand the Mental Health Act inside out.

I live in Canada where the Mental Health Act is jurisdictional by province, so when my daughter and I moved to another province three years ago, I had to get a copy and learn the new one.

In some countries, the Mental Health Act is federal, in other countries it's jurisdictional like in Canada.

You need to find the one where you live. Most of them are online. Print it out and read it. Study it.

It will inform you of:

- your loved one's rights
- your caregiver rights
- the legal rights of the medical system
- the legal rights of the police and the courts

Be warned; it is not happy reading. Nevertheless, know it from top to bottom so that you can advocate properly for your loved one.



RESEARCH HOW TO HAVE AUTHORITY 06. FOR YOUR LOVED ONE

Guardianship/Conservatorship/Power of Attorney/Legal Representation/Community Treatment Orders, etc.

Do what you can to gain legal authority over your loved one so that when they are most unable to care for themselves, you have the authority to get them hospitalized for treatment and/or manage their financial affairs.

This is such a huge issue, because since the legal system does not recognize anosognosia as a thing, our loved ones are expected to make decisions for themselves they are often incapable of doing. We are the ones who end up picking up the pieces over and over again.

To properly take care of your loved one, you need to have the legal right to do so, and unfortunately, sometimes you might need to go to court to accomplish this.

You may be thinking, "I couldn't possibly take my loved one to court. I can't go behind their back and betray them!"

It's very common to feel this way. Here's what I think – you are not betraying your loved one; you are betraying the illness. Ask yourself the questions: Do you want your loved one to have a chance at recovery? Or do you want them to like you?

I decided at one point that I'd rather my daughter hate me and recover, than love me and stay sick. Luckily for us, she recovered enough to know what happened and she is grateful I stepped in and took charge at a time when she was incapable of being in charge of herself. She honestly doesn't remember much of what goes on during psychosis anyway, so I was far more worried than I needed to be.

I acknowledge that it also takes a lot of courage to go through an adversarial system if you are not an adversarial person, but consider what will happen if you don't.

Again. All of this is jurisdictional. It's different wherever you live in the world. Research what is possible in your jurisdiction and actively go after it to the best of your ability.

These are some of the possibilities:

- Conservatorship
- Guardianship
- Power of Attorney
- Enduring Power of Attorney
- Legal Representation
- Community Treatment Orders





LOCATE ALL THE HELP AGENCIES

07. WHERE YOU LIVE

Help agencies are out there. You need to find them, not just for your loved one, but for your own well-being. These groups can become part of your loved one's care team, which helps ease the workload for you.

Help agencies are usually funded by public funding or private donations and are often staffed by volunteers, or a mix of paid and volunteer staff. They are free to you.

They range from offering group support, peer support, education groups, art therapy, housing support, and other types of support.

In Canada, we have the Schizophrenia Society of Canada. Each province has a chapter and there are some local chapters here and there as well. Agencies like this often have group programs for people with this illness as well as for their caregivers and families.

<https://schizophrenia.ca/>

In the United States there is the National Alliance on Mental Illness.

<https://www.nami.org>

Australia has the Schizophrenia Fellowship

<https://www.nps.org.au/australian-prescriber/articles/schizophrenia-fellowship>

I can't list all the agencies where you live, you'll need to do this yourself, but the point is, you don't have to do everything alone!

Create a list of who can help your loved one and who can help you, so that you can talk to someone and ask for help when you need it.

Look for:

- Mental health agencies
- Home support agencies
- Caregiver support agencies
- Financial support agencies
- Legal support agencies





RESEARCH GOVERNMENT BENEFIT 08. PROGRAMS

Some governments have disability benefits programs, and if your government has any, do what you can to apply for them on your loved one's behalf.

How do you find out what's available?

- Ask any of the agencies you contact
- Ask your loved one's doctor
- Ask the nurse at the clinic
- Ask everybody you come into contact with

If you can, gain financial control over these benefits, which I recommend you do because when your loved one is in psychosis, they may lose the ability to pay their bills.

I had to bail out my daughter a few times when she spent her rent money on everything else but her rent. Then I found out I could become her financial manager. Her benefits were paid directly into a special account so I could pay her rent and give her weekly spending money. I was audited regularly to make sure I was doing things correctly, but that was a small price to pay for my own peace of mind.

Benefit programs to look for:

- Disability benefits
- Housing benefits
- Medical benefits
- Dental programs
- Transportation benefits
- Support benefits
- Tax credit benefits





09. PUT TOGETHER A CARE TEAM

“Many hands make light work”

I can't stress this enough. Caregivers tend to try to do things on their own, me included, but it's not healthy for you in the long run. You will burn out.

You need a break, so it's vital that you find other people to whom you can delegate some of the care load.

Do not be afraid to ask for help!

Make a list of what you wish you had help with and start looking for people who can fulfill those tasks.

A care team might include:

- Medical care team, of course
- Case worker/Social worker
- Home care worker
- Family and friends that will take your loved one to a regular activity
- Supportive programs that offer activities such as:
 - art therapy
 - movement therapy
 - animal therapy
 - etc.
- A cleaner for your home
- Someone to mow the lawn (like a local teenager)
- Someone to do regular maintenance on your house
- Delegation of chores to other members of the family





10. STREAMLINE THE REST OF YOUR LIFE, AS MUCH AS YOU CAN

Don't underestimate the power of simplifying the management of your home.

As a caregiver, you are already busy enough, so having your home running efficiently in the background frees you up for more self care time.

It bothered me that when my daughter was at the worst of her illness, I lost control of my house. As a single parent, I was caring for her, working 60 hours a week, and also had two other children to care for. The stress was overwhelming. I realized that I couldn't live like this forever, so I created some streamlining strategies that helped me manage my home and reduce my stress level.

For example, I wanted to eat better, so the first thing I did was create a complete menu plan for all meals for 14 days, including a detailed shopping list. I split the 14 days into Week 1 and Week 2 and re-used these plans over and over again for years.

What this did for me was to eliminate time and stress worrying about what's for dinner. I have a plan and I have the ingredients. No extra thinking involved.

When you streamline the management of your home, you stop spending any brain energy worrying about it. It's as simple as that.

Once you streamline one thing, move onto another. In the end, your home will be so much easier to manage and you will feel like you are in control.

Don't forget, you could also enlist the help of friends to help you out!

Here are some examples of areas you could streamline:

- Create a weekly menu plan you shop with - to stop having to think about what's for dinner
- Declutter your home - to make tidying and cleaning easier
- Organize your home files - so you can find important papers
- Create a cleaning chart - and delegate tasks
- Clear out your garage or basement - get rid of everything you don't want to spend time and energy caring for anymore
- Clear out your clothes closet - get rid of everything that you don't like or doesn't fit. You are an important caregiver. You deserve to feel good in your clothes!
- Streamline anything else that would make a difference to you - what would that be?



A FINAL WORD

My intention for creating this booklet is to help simplify what I think you need to know as a Caregiver of someone with Schizophrenia Spectrum Disorder. If I'd been handed this **Action Guide** when I first started out, I know my path would have been easier, at least from the point of view that I would have known what to focus on.

You don't have to take all of these actions, but if any one of these helps you out, then you will gain some control over the situation.

The path of the Caregiver is a difficult one, and we are, in my mind, among the unsung heroes of the world. Knowing this doesn't give me much comfort, because what you and I really need is for our community to care about us and our loved ones, and offer the support we really need.

My intention and passion going forward is to be a part of the change that:

- Helps Caregivers like us get to know each other, support and learn from each other
- Demystifies Schizophrenia Spectrum Disorders and eradicate stigma
- Amends Mental Health Acts to take Anosognosia into consideration, and give authority to Caregivers to make medical decisions on behalf of their loved ones.

Bless all of you and please take good care of yourselves,



Juanita Walton

juanitawaltoncoaching.com

P.S. FIND YOUR PEOPLE

Unstoppable Caregivers of Schizophrenia:

I invite you to join my private Facebook group where we join other caregivers to talk about all the issues related to our caregiving and our loved ones.

<https://www.facebook.com/groups/539960384174194>

Group Coaching:

If group coaching is what you need, check out my group coaching programs.

www.juanitawaltoncoaching.com/group-coaching

Juanita Walton Coaching:

I also invite you to reach out to me if you need more individual support. First session is free.

www.juanitawaltoncoaching.com/free-consultation

