

A Guidebook for Creating a Mental Health Advance Plan or Psychiatric Advance Directive



**The easy-to-use planning guide for people who want to maintain a voice in their
mental health care and life choices during times of illness or hospitalization**

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ADVANCE SELF-ADVOCACY PLAN

ABOUT THIS GUIDEBOOK

The Advance Self-Advocacy Plan Guidebook was developed by the University of Pennsylvania Collaborative on Community Integration for Individuals with Psychiatric Disabilities as a consumer- and provider-guided tool that:

- can be used as a legally binding psychiatric advance directive (PAD) if the plan creator chooses to do so;
- emphasizes the value of the planning process, as separate from the legal aspect, of creating an advance plan to be used in the event of a future mental health crisis;
- addresses advance planning needs in a simple, inviting and easy-to-use format; and
- includes topics that are not addressed well or at all in other mental health advance planning documents.

We hope that with this practical, user-friendly tool, advance planning will be accessible to more people who are concerned about, and want to provide instructions for, their future mental health needs.

Please note that the ASAP Guidebook and Plan forms do not constitute legal advice. State laws vary and it is possible that part or all of this document will not be effective in your state. It is recommended that you consult a lawyer or legal resource before you assume that your Advance Self-Advocacy Plan will be legally valid in your state as an advance directive.

You can find state-specific information about the legal requirements for psychiatric advance directives in the state where you live at www.NRC-PADS.org.

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TABLE OF CONTENTS

PART I: LEARNING ABOUT ADVANCE PLANNING

INTRODUCTION	5
What is an Advance Self-Advocacy Plan (ASAP)?	
Why Make a Plan Now?	
YOUR ASAP CAN BE USED IN SEVERAL WAYS	7
As a Planning Tool	
As Instructions for Others During a Hospitalization	
To Prevent Being Hospitalized	
As a Legal Document (Psychiatric Advance Directive)	
ADVANCE PLANNING OPTIONS	8
- You Can Make Choices About Your Future Mental Health Care	8
- What Kind of Advance Plan Works Best for You?.....	8
- Which Planning Option Is Right for You at This Time?.....	9
- My Choice of Advance Planning Option	10
KEY CONTRIBUTORS TO YOUR ASAP	11
I STILL HAVE SOME QUESTIONS	12
Must I Complete Every Section of the ASAP?	12
Can I Change or Update My ASAP?	12
How Can I Get Motivated to Create an ASAP?	12
Suggestions for Working on Your Plan	13
PART II: CREATING YOUR OWN ADVANCE SELF-ADVOCACY PLAN	
SELF-ASSESSMENT	14
When I'm Feeling Well!	15
How to Know When to Use My ASAP	16
MAKING CHOICES ABOUT HOSPITAL TREATMENT	17
APPOINTING A MENTAL HEALTH CARE REPRESENTATIVE	18
GETTING THE MOST OUT OF YOUR HOSPITAL EXPERIENCE	19

TABLE OF CONTENTS (continued)

KEEPING YOUR LIFE ON TRACK	21
Caring for Your Children	21
Caring for Your Home & Mail	24
Caring for Your Pets	24
Taking Care of Your Finances	25
KEEPING YOUR JOB and/or EDUCATION ON TRACK	26
Keeping Your Job on Track	26
Keeping Your Education on Track	27
PLANNING SUPPORT MATERIALS	30
TIPS: Some Things to Keep in Mind While Creating Your ASAP	30
Additional Resources.....	30
Emergency Contact Cards	31
ASAP “Find It” Sheet	32
Use this to keep track of information that you need to find that will help you complete your plan,	

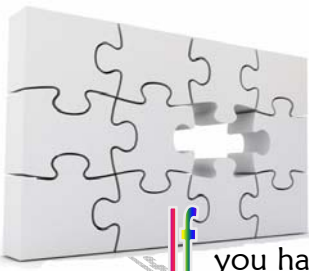
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Jeffrey Draine, PhD, and Mark Salzer, PhD, whose concept of an advance self-advocacy plan (ASAP) as a guide for consumers that presents a range of advance planning options to choose from — including, but not limited to, the psychiatric advance directive — initiated the efforts for this project; Mary Jensen, CRSS, RN, Seble Menkir, MS, and Myron Page, BA, whose reviews and suggestions ensured that the guidebook maintained a recovery- and strengths-based orientation; the Certified Peer Specialist Professional Development Groups of Philadelphia and Montgomery Counties in Pennsylvania, and the clinical staff of Montgomery County Emergency Services and Central Montgomery Mental Health/ Mental Retardation Center, all of whose contributions were critical to developing the content of the guidebook; Arlene Solomon, CPRP, CRC, and Debbie Plotnick, MSS, MLSP, LSW, who provided helpful feedback on preliminary drafts; and Jenna Shawl, whose reading of the manual helped to ensure that the concepts and language were easily read.

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PART I: LEARNING ABOUT ADVANCE PLANNING

INTRODUCTION

If you have been hospitalized for mental health care in the past and believe you might be hospitalized again in the future AND you want to let people know which treatments you prefer and which you want to avoid...

If you want to make others aware of medications that are helpful for you and also tell them about medications that you need to avoid...

If during a time of great stress you have found it difficult to make good decisions about your mental health treatment OR a doctor has determined that you are not competent to make these decisions...

If you answered “YES” to any of the above statements...

Then creating your own plan NOW about how you want to be treated in the future keeps you in the center of your care (in the driver’s seat, so to speak!) should your mental wellness take a turn for the worse. This is called advance planning. An advance plan can:

- Ensure that your preferences about your mental health treatment are known, even at times that you are not able to discuss them;
- Help you organize and prioritize the important responsibilities in your life;
- Inform others about how to take care of your family, home, financial and work responsibilities;
- Be a source of useful information that is available whenever you need it; and
- Give you peace of mind that you have a plan in place that you, and those helping you, can rely upon.

What is an Advance Self-Advocacy Plan?

Unlike mental health treatment plans that are developed for you by another person (such as your doctor, case manager, or therapist) **this is a plan that you create for yourself to handle your future needs**. Taking responsibility and action to help yourself is called self-advocacy. Therefore, we have named this advance planning tool an **ADVANCE SELF-ADVOCACY PLAN** or “ASAP” for short.

This ASAP Guidebook will help you create a comprehensive plan that addresses your unique mental health and lifestyle needs in the event of a future mental health crisis. It is a companion to the user-friendly ASAP Planning Sheets that you can use to write down your personal plan.



Change is inevitable, except from a vending machine.
- Anonymous

Your ASAP can instruct others about what to do if and when you experience a mental health crisis. Because your instructions are there to inform them, psychiatric treatment staff, as well as other people whom you want involved (such as family and friends), can act quickly to ensure that your needs are addressed as you would like them to be. An ASAP can help you to receive the treatment that you want, even when it seems like things are out of control!

Why make a plan now? I feel just fine and don't like thinking about being ill because it makes me feel bad.

It's wonderful if you are feeling well right now! And guess what? When you're feeling well is the BEST TIME to make a plan for when you are NOT feeling well. Why? Because when you are feeling calm and in control, you can think most clearly about what worked well for you — and what didn't — during past crisis episodes.

Everyone's life is somewhat unpredictable and we can never be sure what turn of events might take place. Everything could be going along smoothly, and then some big change can come along and cause our comfortable pace to stutter or stop.

Life changes can affect our mental health in both positive and negative ways. For those of us whose mental wellness is frequently challenged, changes can sometimes lead to a crisis. If your ASAP is put into action, and your instructions are honored by treatment professionals and others who have agreed to help, it can significantly reduce the negative effects of a crisis.

In this context, "ASAP" stands for the **ADVANCE SELF-ADVOCACY PLAN** that this guidebook can help you create. Did you also know that the letters A-S-A-P stand for the well-known expression "As Soon As Possible"? If you decide that creating an advance plan is a good idea, then doing it As Soon As Possible (ASAP) will ensure that you are prepared if life takes an unexpected turn. It is our hope that you never need to use your plan. But we also hope that you will have an ASAP ready if you ever need it.

Being Prepared...

A lot of people ask me if I were shipwrecked, and could have only one book, what would it be? I always say "How to Build A Boat." - Stephen Wright



YOUR ASAP CAN BE USED IN SEVERAL WAYS

Beyond offering forms for completion, your Advance Self-Advocacy Plan (ASAP) is an advance planning tool to help you think about, discuss and record how you want to handle your responsibilities and medical treatment should you experience a mental health crisis of any degree. It can be used in a number of ways:

- ◇ First, it will help you take stock of what you need for yourself and from others when you are heading into, or are experiencing, a mental health crisis.
- ◇ It can be used during a hospitalization if you have been judged to lack the **capacity** to make decisions regarding your own mental health treatment. It will inform crisis and hospital staff about your treatment preferences and ensure that your voice is heard.
- ◇ It can be used as a practical framework and plan of action if you are in a “pre-crisis” state where you are having difficulty thinking clearly about what to do but want to avoid being hospitalized.
- ◇ Lastly, your ASAP can serve as a legally binding document, called a Mental Health Advance Directive or **Psychiatric Advance Directive (PAD)**. This document makes it mandatory for mental health service providers to honor your preferences and requests if your state recognizes this type of directive as a legal entity.
- ◇ The National Resource Center on Psychiatric Advance Directives Web site (www.nrc-pad.org) has an up-to-date list of states that legally recognize Psychiatric Advance Directives, as well as general and state-specific information about PADs.

Capacity is the basic ability to understand a diagnosis and to understand the significant risks, benefits, and alternative treatments of mental health care. It also includes the ability to understand the consequences of not receiving treatment.

Psychiatric Advance Directives (PADs) are a type of medical advance directive, somewhat similar to a living will.

The National Resource Center on Psychiatric Advance Directives defines PADs as:

“relatively new legal instruments that may be used to document a competent person’s instructions and preferences regarding future mental health treatment. Psychiatric advance directives can be used to plan for the possibility that someone may lose capacity to give or withhold informed consent to treatment during acute episodes of psychiatric illness.”



ADVANCE PLANNING OPTIONS

You Can Make Choices About Your Future Mental Health Care

It is your right to choose what types of medical and psychiatric treatment you prefer in case you become ill. This right is supported through federal and state policies and laws (such as the Americans with Disabilities Act and the federal Patient Self-Determination Act) and through legal means by creating a psychiatric advance directive (see page 7) and/or by appointing a **mental health care representative**.

A Mental Health Care Representative (also called mental health care proxy, agent, surrogate or attorney-in-fact) is a competent adult who is 18 years or older whom you designate to make treatment decisions on your behalf in the event that you are unable to make competent decisions during a mental health crisis.

What Kind of Advance Plan Works Best for You?

There are four main ways that you can approach advance planning for your medical and psychiatric health care:

Option #1

Do nothing at this time; leave things the way they are.

If you are uncomfortable expressing your preferences about treatment, it is your right not to make any plan at all. If it is determined that you lack the **capacity** to make decisions for yourself, then decisions regarding your treatment will be in the hands of other people. You might not have any say at all about what treatment you receive when you are in crisis.

Option #2

Talk about your treatment preferences with people whom you trust so that they are aware of what you need if the symptoms of your illness become serious. These people can inform treatment staff about your preferences if your condition makes it difficult to clearly communicate these yourself.

This option provides more information about your needs than having no plan at all and crisis response personnel might be willing to consider requests made by others on your behalf. However, without some written proof that you have given permission for a particular person to speak for you, crisis staff have no obligation to consider their requests.

Which Planning Option Is Right for You at This Time?

Think about each of the planning options below and, if possible, discuss the pros and cons of each one with someone you trust. Then circle how comfortable you are with each option.

Option #1: Do nothing at this time; leave things the way they are.

Very Comfortable	Somewhat Comfortable	Somewhat Uncomfortable	Very Uncomfortable
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Option #2: Talk about your treatment preferences with people whom you trust

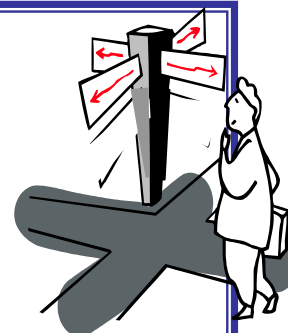
Very Comfortable	Somewhat Comfortable	Somewhat Uncomfortable	Very Uncomfortable
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Option #3: Create a written plan that communicates your preferences and share it with people whom you trust.

Very Comfortable	Somewhat Comfortable	Somewhat Uncomfortable	Very Uncomfortable
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Option #4: Make your plan legally binding with a Psychiatric Advance Directive.

Very Comfortable	Somewhat Comfortable	Somewhat Uncomfortable	Very Uncomfortable
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Option #3

Create a written plan that communicates your preferences and share it with people whom you trust.

This involves three simple steps:

- (a) think about what happens when you start to experience troubling symptoms,
- (b) figure out what needs to be done to help you recover, and then
- (c) use this information to create a written plan that communicates your needs and treatment preferences to others.

Your written plan can usually be used as a legal document when it is signed and dated by you and witnesses (see Option #4). A legally binding plan is called a Mental Health or Psychiatric Advance Directive.

Option #4

Make your plan legally binding with a Psychiatric Advance Directive (PAD).

Create a written plan that includes your treatment preferences (as in Option #3) and/or names a mental health care representative to speak on your behalf.

To become legal, an advance directive must be signed and dated by you and usually by two adult witnesses of your choice.

Witnesses must agree that you were not forced to write anything that goes against your wishes. In some states your plan can be notarized without witnesses and in some states you must have two witnesses plus a notary.

Once your plan becomes a legal document, it must be followed by medical and psychiatric treatment staff to the best of their ability.

*Choice is the rudder that
guides each person's des-
tiny.*

- Peter Megargee Brown

Note: On the previous page, if you circled the same comfort level for two or more options, it is better to choose the one with the higher number as the option you will use for planning purposes.

(For example, if you chose “Very Comfortable” for both Option #2 and Option #3, Option #3 is the type of advance plan you’ll want to use at this time.)

We encourage you to look through this Guidebook and fill out useful information in the companion Advance Self-Advocacy Plan before making a decision about which option you will choose. Then, revisit these options to see which advance planning option is right for you at this time.

After looking through this guidebook and filling out plan information that is useful to you, which Planning Option is right for you at this time?

Again, think about each of the planning options on pages 8 and 9. Then, indicate which option you would like to put into action at this time.

My Choice of Advance Planning Option:

I am most comfortable with Option # _____, which I would briefly describe as:

Today's Date: _____ . Initials: _____

As time goes on, you might decide that a different Planning Option is a better fit for you. That's fine! In fact, we encourage you to regularly revisit your feelings about how you want to handle your future.

KEY CONTRIBUTORS TO YOUR ASAP



The PLAN CREATOR OR AUTHOR

There is only one person who fits the bill for this role and that's you! You are creating a plan for yourself, a self-advocacy plan, that is based upon *your knowledge, feelings and experiences*; therefore **YOU** are the **PLAN CREATOR**. Develop this plan when you are feeling well. You can get input from other people; however, the final plan must be one that you are comfortable with.

Your PLAN ASSISTANT (or ASSISTANTS)

Anyone who helps you produce your plan can be considered your “plan assistant.” You might want to have several assistants, each of whom can offer help in different ways. Your assistants can:

- help you to obtain information that you need for developing your plan (such as contact information, financial information, information about treatment options, medications taken and hospitalizations, etc.);
- be a “sounding board” for your ideas;
- help you to remember details from your past experiences that can inform the choices you include in this plan; and
- discuss the pros and cons of different ideas with you as you develop your plan.

Your friends, family members, your doctor, your care manager – really, anyone who knows you well and whose information and opinions you trust – can help as your plan assistant.

Your SUPPORT PERSON (or SUPPORTERS)

A Support Person is someone who helps you carry out your plan, should that become necessary. You can have more than one support person; in fact, dividing the responsibilities for different aspects of your plan will make it easier for each individual to help you. For instance, you can ask one supporter to notify others that you are in the hospital and/or need help, while other supporters could care for your children, pets or finances while you are away from home.

It's a good idea to ask someone to be your **Primary Support Person**. S/he would be the first person contacted if your plan needs to be put into action. Your Primary Support Person should keep a copy of your ASAP so that s/he can let mental health staff and your other supporters know how to assist you. If possible, ask someone to be your back-up or **Alternate Primary Support Person** in case the first person you chose is unavailable.

Ask people in advance if they are willing to be a part of your plan and discuss what you would like them to do, should the need arise. It will be much easier to put your plan into action if the people you name as supporters are aware of their role and have agreed to help out.

*To be trusted is a greater
compliment than to be
loved.*

- George MacDonald

*One is taught by
experience to put a pre-
mium on those few people
who can appreciate you for
what you are.*

- Gail Godwin

MENTAL HEALTH PROFESSIONALS

These folks are partners in your mental health care. Your mental health partners can:

- discuss the issues and challenges that you are facing and explore ways to find solutions to these challenges;
- teach you about medications and treatment options that can help you recover and stay well; and
- help you explore and understand your psychiatric history so that you can better plan for your future.

I STILL HAVE SOME QUESTIONS...

Q - Must I complete every section of the ASAP?

A - No, it is not necessary to fill out information for sections of the ASAP that do not apply to your particular situation. Just keep in mind that mental health professionals might need to make choices for you in any area about which you do not express a preference. The ASAP can be used by you and others (such as your mental health provider, crisis personnel and others with whom you choose to share it) as a primary reference regarding your mental health care. Your ASAP can also serve as a Psychiatric Advance Directive (see Option #4 on page 9).

Q - Can I change or update my ASAP? If my psychiatric needs or life circumstances change, the plan that I create now might not be useful anymore. When can I update it and do I have to rewrite the whole thing?

A - You can change or update your ASAP any time you want. It's especially good to review and update your plan whenever there are changes in your mental health, your attitudes, the people you are close to, your doctor and/or mental health provider, as well as other aspects of your life. Try to review it at regular intervals, perhaps twice a year, to see if any of your preferences have changed. In most cases you only need to cross out the information that is no longer accurate and replace it with your current information.

Make sure to date and initial your updates so that you and others can quickly identify your most recent changes.

Remember to give the updated ASAP to your Supporters.

Q - How can I get motivated to create an ASAP? It's a good idea to create an advance plan, *BUT...* it seems like a lot of work and what if I really don't FEEL like doing it?

A - It can definitely be hard to get motivated about a subject as serious and uncomfortable as how to handle a future mental health crisis. However, being prepared has its own rewards and, in many cases, you can complete your plan in less than an hour! On the next page are some suggestions to help you create your own plan.

★ Important! ★

If you decide to use your ASAP as a legal document (in states that recognize psychiatric advance directives as legal entities), it's important that you know that some states:

- ◆ require that you update your advance plan *at least every two years*;
- ◆ require that you create a new plan each time that you want to change your current one.

Suggestions for Working on Your Plan:

(1) Start Anywhere: Trust your instincts on where to start. There is no right place to start or right way to write your plan. **You** are the Plan Creator and you can decide!

(2) Reward yourself: Decide on something enjoyable that you can do when you complete your plan. Having something to look forward to can motivate you to start, and complete, this important task.

(3) ASAP Partners: Try working with a partner who is also creating an ASAP. Get together on a regular basis, with the goal of completing one or more sections each time you meet.



It can be helpful and even enjoyable to share stories and ideas with a peer who has had similar experiences. Discuss ways you can each promote your wellness while handling and recovering from a crisis. It's comforting to know that you are not alone in planning for a potentially difficult time.

(4) ASAP Group: The arrangement described above for ASAP Partners can also be done with a small group of people. If you attend a community mental health program, a clubhouse, a residential program or a consumer center, ask other people if they would like to form an ASAP group. You may decide to meet at a local library, someone's home, or other comfortable meeting place. Not only can this make it more enjoyable to complete your own plan, you will also be motivating others to help themselves!

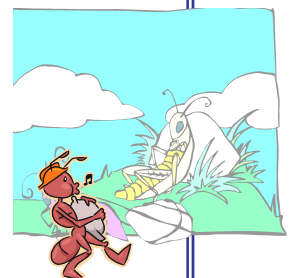


(5) Think about the Grasshopper and the Ant... Be the Ant!

Consider Aesop's famous fable about the Ant, a practical little creature who worked each autumn day to find and store some food. The Ant knew that it would be difficult to get all the food needed once the cold weather arrived. Little by little, the Ant gathered food until it had enough to be prepared for the possibility of a harsh winter.

The Ant's neighbor, the Grasshopper, decided to leave such things to chance and spent time happily resting in the sun or hopping for fun when the mood struck him. "Why waste my time working when I have all the food I need now?" the Grasshopper thought. But when the harsh winter arrived, guess who had enough food to eat?

If you guessed the Ant, then you get the point! You can put your ASAP together a little bit at a time. Before you know it, you will be rewarded with having a plan in case you need it and peace of mind knowing that you are prepared if "harsh" times come your way!



PART II: CREATING YOUR ASAP

SELF-ASSESSMENT

"Normal is just a setting on your dryer." - Patsy Clairmont

Who are you? It's important that providers of mental health services know the difference between who you are normally and who you are when you begin to experience symptoms of an illness. Remember, most of the time, crisis response and hospital staff have never had the opportunity to know you when you are well. They may not be able to tell which aspects of your behavior are normal for you and which aspects indicate that you are experiencing symptoms of an illness.

For instance, if you arrive at the hospital sporting an extremely unusual hairstyle and clothing, this could be interpreted as a sign of mania or psychosis by mental health treatment staff. They might start medication and treatment to address these "symptoms."

But what if these aren't "symptoms"? What if your style preferences are **normally** a little unusual and the way you look has nothing to do with psychiatric symptoms? It's possible that, even with the best intentions, if no other information is available, hospital staff might treat you for an illness that you do not have. Wrong medication and treatment can (and usually do) worsen and/or hide your true symptoms, resulting in a longer, more difficult and less useful hospital experience.

For these reasons, it's a good idea to do a self-assessment and write a brief description of how you usually feel, look or behave when you are well, or at least at your best. It's also very helpful to describe what you're like when you are having distressing symptoms so that people can provide appropriate supports to help you recover.

TIP: Ask people who know you well to work with you on your self-assessment. They might offer some surprising insights into your strengths and challenges that you are unaware of.

*Let us not look back in anger,
nor forward in fear, but
around in awareness.*

- James Thurber

*Some days you are the bug,
some days you are the wind-
shield.*

- Anonymous

*There is no greater delight
than to be conscious of sincer-
ity on self-examination.*

- Confucius

This is what I'm like when I'm feeling well.

This section has two purposes: (1) To give psychiatric treatment staff a picture of who you are when you are well so that, if you are in crisis, they can more accurately distinguish symptoms of your illness from your usual personality. If you can't think of a time when you were well, what are you like when you're at your best? (2) To remind YOU of who you are when you are well, so that you have a healthy reference point when you're feeling bad.

If possible, attach a photograph of yourself in the frame to the right. Choose a picture that you like a lot, one that shows you looking or feeling really good. *It's fine if the photo has other people in it.*

Alternatively, you can attach a picture of people who you care about, your pet(s) or even a beautiful scene or funny cartoon.

In this space, you can attach a photograph of yourself when you were feeling good
OR
a picture of anything that reflects your personality and makes you happy!

You can add a caption to your picture ->

Looking at a picture that makes you happy can remind you that, though life is filled with ups and downs, there were "ups" in the past and there will more be "ups" in the future. As the expression goes: "A picture is worth a thousand words." If at any time you are feeling so down that good words fail you, just look at — and show others — the above picture. It expresses at least a thousand words worth of the "up" you have inside of you.

On your ASAP, write a description of your usual, well self. Be as expressive as you can to give others a sense of who you are. Here are some descriptive words and an example to get you started.

shy	outgoing	stubborn	angry	happy	fairly optimistic
smart	friendly	unhappy	laid back	nervous	fairly pessimistic
neat	messy	well-groomed	quiet	talkative	rather social
calm	jumpy	high-strung	funny	serious	rather unsocial

EXAMPLE:

Although I'm a rather shy and serious person, I try to overcome that and think most people would describe me as funny, friendly and outgoing. I'm detail-oriented and fairly organized but tend to be messy at home. I'm usually optimistic and don't give up easily in challenging situations. I think I have a good sense of humor and enjoy being around smart and creative people.

How to know when to use my Advance Self-Advocacy Plan (ASAP)

The purpose of this section is to help you identify when you might need to put a crisis recovery plan into action. If you have been developing and using personal illness management plans, these strategies might be enough to keep you from entering a crisis situation. However, if these strategies have lost their effectiveness, or if you do not have strategies to use, your ASAP can be put into action.

Experiencing intense, troubling symptoms, harmful thoughts or the feeling that you have lost control of your thoughts and behavior could be indicators that it's time to start using your ASAP. It's a good idea to discuss these indicators with people whom you trust — friends, family, your mental health professional(s) and/or your ASAP Support Person(s) — to determine at what point to put your plan into action. Specific indicators might include:

Feeling hopeless, helpless or useless - racing thoughts - feeling like you can do dangerous things without getting hurt - hearing voices or seeing things that other people don't hear or see - feeling extremely scared, nervous or depressed - sleeping too much or not enough - unusually negative or hostile attitude - withdrawal from friends and activities - neglecting hygiene or living environment - increased drug or alcohol use - wanting to hurt or kill yourself - other indicators or symptoms.

Use your ASAP to describe how you feel and behave when you are heading toward a crisis situation. This will give friends, family and especially those who don't know you well (such as psychiatric treatment staff) an idea of how to tell the difference between your usual personality and what you are like when you might need to activate your plan.

EXAMPLE:

These are indicators that I might need to activate my plan: I become very withdrawn, anxious and easily angered. When I'm in crisis, I will not change my clothes for days at a time. I feel an overwhelming sense of doom and become very pessimistic. Sometimes I feel so scared and depressed that I can't leave the house or even get out of my bed. When I am manic, my mind races and it's hard for me to stop talking. I spend money more freely and buy a lot of the same item. Sometimes I don't sleep for several nights in a row.

TRIGGERS, SYMPTOMS AND HELPFUL ACTIONS: In the language of mental health and recovery, “triggers” are situations, events or people that can cause you to experience disturbing symptoms. Helpful actions are those that can reduce the intensity of negative symptoms to help you regain healthy control of your thoughts and behaviors. When you (and/or those who want to help you) engage in helpful or protective actions, you can sometimes keep hold of your mental wellness, even in the face of difficult situations and troubling symptoms.

You can use your ASAP to describe helpful actions that can lessen the impact of particular symptoms or triggers. Below is an example of how you might write this information in your plan.

EXAMPLE:

If I experience the following feeling or situation: → This action will help me to feel better:

If I'm too scared to leave my home...

Have a friend or relative ask me to come help them with something.

MAKING CHOICES ABOUT HOSPITAL TREATMENT

Making your own decisions about specific aspects of a psychiatric hospitalization has the potential to significantly enhance your recovery from crisis and shorten your stay in the hospital. Having your choices known can also protect you from ineffective, unwanted, or possibly harmful treatment or actions. Involuntary treatment or interventions such as seclusion and restraint could possibly be avoided.

Your Advance Self-Advocacy Plan (ASAP) provides a way for you to plan ahead and describe the kinds of mental health treatment you want to receive if you are hospitalized and unable to communicate for yourself or make voluntary decisions. Writing down your treatment choices or instructions accomplishes two things: (1) it will ensure that your preferences are known and (2) it will give hospital staff a personalized plan that they can use to help you get the most out of your hospitalization.

Is it important for other people to have a copy of my ASAP besides me?

Yes! It is very important to give back-up copies of your ASAP to people whom you trust, such as friends, family and the mental health professionals who are working with you. Why? It's good to have a replacement in case your personal copy gets misplaced or lost. In addition, during a crisis, you might not be able to easily locate or have access to your own copy. It's also a good idea to have more than one person keep a copy of your ASAP in case your primary support person is unavailable or cannot be reached.

It is also important that there are other people (besides you) who can use your ASAP to advocate on your behalf. Their copies let them know exactly what kind of care you want so that they can knowledgably guide or persuade hospital staff, even if you decide not to use your ASAP as a legal document (a psychiatric advance directive). Remember, there is power in numbers and the more people who are aware of your needs, the better chance there is that your treatment requests will be honored.

What kinds of choices can I make about the kind of treatment I receive when I'm in the hospital?

- ◇ You can make choices about which hospitals, doctors and medications you do or do not want during a crisis.
- ◇ You can let clinical staff know how you need to be cared for or treated in terms of therapy (including electroconvulsive therapy or ECT), experimental drug and treatment trials and the use of your personal recovery, safety, illness management or wellness plans. You can specify the conditions under which interventions such as seclusion or restraint might be used, if at all.
- ◇ You can direct whom you want or do not want notified about your hospitalization, and how much information you are comfortable sharing with them.
- ◇ You can also choose to have another person (who is called your mental health representative or proxy) make the above decisions for you.

APPOINTING A MENTAL HEALTH CARE REPRESENTATIVE

What is a mental health care representative and why would I need one?

A mental health care representative (also called a mental health care agent, proxy, or attorney-in-fact) is someone whom you choose to make treatment decisions for you in the event that you are not able to make these decisions for yourself.

If it is determined that you lack the capacity to understand your diagnosis and/or the significant risks, benefits and alternative treatments for your mental health care, your representative should express your interests and concerns exactly as you would if you were able to do so yourself. When you appoint a representative, you are giving that person legal authority to make mental health care decisions on your behalf.

It is your representative's responsibility to ensure that the choices you've made in your psychiatric advance plan (such as your ASAP or psychiatric advance directive) are known to the mental health professionals who are treating you.

Do I need to appoint a mental health care representative in order for my psychiatric advance plan or directive to be followed?

In states that legally recognize psychiatric advance directives, it is not necessary to have a mental health care representative. However, there are good reasons to appoint someone to represent your interests even if it isn't required that you do so (see below). In states that do not legally recognize psychiatric advance directives, appointing a representative is the best way to ensure that your treatment preferences are known and implemented.

Who can I ask to be my mental health care representative?

It's best to ask someone who knows you very well and has a good understanding of how your mental health condition affects your life. This could be a family member or friend. However, asking someone whom you trust and interact with frequently might be a better choice than a family member or friend whom you rarely see. Your **Primary Support Person**, if you have selected one, might be a good choice for this important responsibility. (Your Primary Support Person is the person who would be contacted first in case of an emergency or crisis... see page 11 for more information). **IMPORTANT: Any person who provides you with mental health services, such as your therapist, psychiatrist or case manager, is NOT allowed to serve as your mental health care representative.**

If I appoint a mental health care representative, will I still be able to make decisions concerning my treatment?

The short answer is yes... if you decide in advance how much authority and flexibility to give your representative when you create your written plan. You can decide whether you want your representative to make all or just some of the decisions concerning your mental health treatment. Your representative cannot override any of your written directives unless you expressly state in your plan that you agree to this.

It's recommended that you put your preferences in writing for those treatment options that you feel strongly about. You can then leave other options open for your representative to decide, when and if it is necessary. This arrangement – having a written plan as well as a mental health care representative – offers the most flexible way to ensure that your needs are met.

GETTING THE MOST OUT OF YOUR HOSPITAL EXPERIENCE

Discussions with people who have experienced psychiatric hospitalizations revealed that many felt that they were no better off after their hospitalization than before. Some even felt that their hospital experience was so stressful that they were in worse shape after their discharge from the hospital than when they were first admitted.

In some cases, people had to be re-hospitalized because they gained little or no lasting benefit from their previous hospital stay. This is a costly, “no win” situation for everyone concerned.



Perhaps you can identify with some of the problems described below that many people have experienced during their hospitalizations:

- ◇ not being allowed to employ wellness techniques that helped them regain their mental balance (such as listening to music, taking walks outside or having some “alone” time).
- ◇ worrying so much about issues that they had to face immediately after discharge that they couldn’t concentrate on their treatment and recovery (issues such as having a place to live, family problems, or being able to afford medication).
- ◇ complications in medication, diagnosis and/or treatment, especially in situations where treatment staff were not aware of their patients’ use of prescription or street drugs. Complications sometimes included being misdiagnosed and/or being prescribed medications that caused allergic reactions, were different than medications they needed and were prescribed by their outpatient physicians, or interacted badly with the medication/street drugs taken before they were admitted.
- ◇ feeling so “over-programmed” during their hospital stay that they had no time to address whatever caused them to be hospitalized. (People often felt “over-programmed” in the sense that they were required to attend so many groups, therapy sessions and activities throughout the day that they had no time for restful reflection about their difficult issues.)

Your ASAP gives you the opportunity to address these kinds of concerns in addition to the planning choices described on page 17. We encourage you to include anything that that can positively or negatively affect your recovery in the hospital. Your hospitalization can be far more effective if the hospital staff know how they can best help you. Your ASAP will help them to help you!

It’s a good idea to decide as soon as possible (yes, ASAP... pun intended!) so that you, and your supporters, are prepared in the event of a future mental health crisis. You can change your treatment preferences or choice of a mental health representative anytime you wish... so *why wait?*

KEEPING YOUR LIFE ON TRACK

Keeping Your Family, Your Home, Your Job and Your Education Safe While You Are Getting Through a Crisis or Receiving Inpatient Treatment for Your Mental Health

It's enough of a challenge to get through a mental health crisis without having to worry about your other responsibilities and your continued recovery. If you need to be away from home for mental health treatment (or if, for another reason, you are temporarily unable to take care of your responsibilities), it will give you peace of mind to know that your home, your children, your pets, your bills, and your other responsibilities will be taken care of in your absence and/or while you get "back on your feet."



The following sections give you the opportunity to note the things that you might need help with and the person or people you would like to provide that help.

CARING FOR YOUR CHILDREN

Having someone whom you trust to care for your child or children if you become temporarily incapacitated will keep them safe and give you peace of mind. It will help them to handle this separation better if they know that you made this decision because you love them and want to ensure their well-being.

There is another important reason for choosing another responsible adult to care for your children while you recover: Losing custody of your children is a real possibility when you are incapacitated unless you have made an advance plan for their care and safety. Custody loss by parents diagnosed with mental illness happens much more frequently than for the general public.

This section gives you the opportunity to think about and choose the best person or people to provide good, safe, temporary care for your child/children. You can also provide important information about each of your children that can help their temporary caregiver and/or your mental health services provider know how to best support them.

Note: If you don't have children who need to be cared for in your absence, please skip to the next section.

*It's important to let your children know that this is a **TEMPORARY** short-term arrangement. Reassure them, as well as the person who will care for them, that you will be back to take charge as soon as possible.*

This could also be done with letters to each child, prepared ahead of time, when you are feeling calm and clear about what you want to tell them.

It's a good idea to talk to your children about whom they feel most safe and comfortable with when they can't be with you; try to take their feelings into account when deciding who should care for them. However, it is more important that their caregiver is someone you trust than that s/he win a popularity contest with your kids.

Below are **EXAMPLES** of the sections in your **ASAP** planning document that detail who should or should not take care of your children. We also present some ideas for you to consider when you decide how to create this section of your plan. Provide as much information as you can to help ensure that your loved ones will have the least disruptive experience possible during this difficult period.

EXAMPLE:

If I am temporarily unable to care for my child/children, please immediately contact my child's/children's other parent or other close family member (named below) to take charge of their care.

Name: _____

Relationship to Child: _____

Phone Number(s): _____

Address: _____

Under NO circumstances should my child/children be given to, or placed in the custody of, the following person (people):



Children's Protection Services are least likely to get involved if you choose a temporary caregiver who is either your children's other parent or another close adult family member. This is not guaranteed; however, it is a better bet than not having anyone chosen in advance to care for your children.



It's a good idea to identify more people as back-up caregivers in case the first person you name is not available when you need this type of assistance.

Make a list here of several people whom you want to consider for the important role of caring for your child in your absence. Think about family members, friends, religious affiliates, and the families of your children's friends as possibilities.

Choose those people from your above list you feel would be the most able to handle this important task and list them on your Plan in order of preference. It's important to ASK each person on your final list if he/she is willing to accept this responsibility if necessary.

EXAMPLE:

In the event that I am temporarily unable to take care of my children AND my children's other parent is unavailable, unwilling or not allowed to have temporary custody, please contact these people (in the order indicated) to care for my children :

Name: _____

Relationship to Yourself and/or Child: _____

Phone Number(s): _____

(Your Plan has space to list four people.)



Having the people you have selected sign or initial next to their names will ensure that they are aware of your request; however, this is completely up to you and is neither a requirement nor a guarantee of their assistance nor is it legally binding.



If there is no one you know well enough to care for your children, try to find a "respite care" agency in your area. Placing your child in respite care can be a more reasonable alternative to calling the government-run Children's Services office. Ask someone to assist you in looking for respite care. There are not many of these wonderful places around, but you might be lucky enough to have one near you.

It's to be expected that your children might be confused and upset if a separation is necessary.

Having some basic information about them can help caregivers support your children more appropriately during this difficult period. This information can be especially helpful for anyone who doesn't know your children but needs to interact with them in the early stages of this transition (such as crisis team or hospital personnel).

EXAMPLE:

Important information about my child or each of my children:

Name: _____ Age: _____

Birth Date: _____ School and Grade: _____

Medical condition(s) and medication(s): _____

Personality and/or other information: _____

CARING FOR YOUR HOME & MAIL:

HOME NEEDS: Home needs might include care of your plants, turning lights on or off, mowing the grass, etc. You can jot down some ideas here about what home needs should be taken care of in your absence. Then use your ASAP to write instructions about how these responsibilities should be handled and who you would like to handle them.

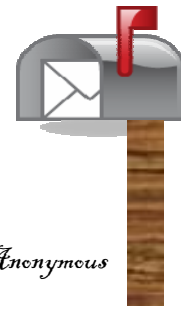


MAIL: If you have a mailing address, you're going to get mail! If your mail accumulates while you are away, it advertises your absence and could leave your home open to theft. It's a good idea to have your mail collected or held in your absence. Either have the post office keep your mail until you return or ask one of your Support People to handle it.

On your ASAP, indicate how you would like your mail handled.

*Bills travel
through the mail
at twice the speed
of checks!*

- Anonymous



CARING FOR YOUR PETS

You will want to make sure that your pets are being cared for properly in case you are ever temporarily unable to take care of them yourself. Use your ASAP to provide contact information for the Support Person (or People) who you would like to care for your pets. You might also want to list the veterinarian and/or a boarding facility that you have used in the past. Then list each pet's name, type of animal, and care needed. If you have more than three pets, attach additional pages to provide information about them.



EXAMPLE:

Pets Support Person #1: _____

Phone Number(s): _____

Pet #1 - Name: _____ Type of Animal: _____

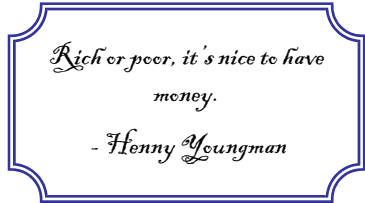
Care & Feeding Information _____

*Outside of a dog, a book
is a man's best friend.
And inside of a dog, it's
too dark to read.*

- Groucho Marx

TAKING CARE OF YOUR FINANCES:

Even under the best circumstances, many people find it difficult to stay on top of their financial responsibilities. When you are experiencing a crisis, this task can seem overwhelming! Try to keep in mind that taking care of your rent or mortgage and other payments will, in the end, be FAR LESS STRESSFUL than neglecting them. (Think of the old adage “The only problems that go away with neglect are rotten teeth!”)



Having a list of your important monthly financial responsibilities will make it easier to keep them organized on a regular basis. This list will also help you to quickly identify those payments that need to be addressed during a crisis period.

IMPORTANT: If you want or need to have someone else take care of your financial responsibilities, you will need to either (1) appoint someone to have power-of-attorney authority over your financial affairs or (2) give a trusted friend or family member your bank account (and possibly social security) information so that they can make these payments for you.

Do You Have a Representative Payee? (This is someone who has the legal right to take care of all your money matters on your behalf.)

Your ASAP has a place for you to write down the contact information for your representative payee. You can also initial whether you do or don't want to have him/her told if you become hospitalized.

You can create a handy reference of your monthly payments in your ASAP. You can use this reference at any time (whether you are in crisis or not). It can also be used by anyone you appoint to temporarily make payments for you. Your ASAP will have a place to record the following kinds of information:

EXAMPLES:

RENT OR MORTGAGE PAYMENTS:

Name of landlord, rental or mortgage company: _____

Phone / Mailing address: _____

On the _____ day of the month, I pay the following amount: \$ _____

BILL PAYMENTS

Type of Bill (water, electric, phone, etc.)	Account Number	Due on This Day
_____	_____	_____
_____	_____	_____

KEEPING YOUR JOB AND/OR EDUCATION ON TRACK

You will want to make sure that your job or educational program will still be there for you when you are ready to return after an absence due to a mental health crisis or for ANY reason. Letting your employer or educational institution know that you will be gone can prevent the termination of your job or loss of your student status and protect your future.

THE MOST IMPORTANT THING YOU CAN DO to make sure that your job or educational program will be waiting for you after an extended absence is this:

IMMEDIATELY NOTIFY THE APPROPRIATE PERSON OR DEPARTMENT THAT YOU WILL BE "OUT SICK."

KEEPING YOUR JOB ON TRACK

It can be uncomfortable – even scary – to call your supervisor to say that you won't be coming in to work. You know in advance that s/he won't be happy with the news and will probably ask questions about your absence that might make you even more uncomfortable!

But, no matter how distasteful or scary it is for you to notify your workplace that you cannot be there, it is **EXTREMELY IMPORTANT** you do that. If your employer hasn't heard from you within a defined period of time, your absence can be considered "job abandonment." *You can be fired for this!*

What to do: As soon as you know that you will be missing work, call your employer or ask a trusted Support Person to call for you. Your Support Person could say something like:

"My name is Susan Smith and I'm calling to let you know that John Jones will be out sick for a while. I'm not sure how long he will be gone, but I will be in contact with him or his doctor and will keep you posted. Here is a phone number where you can contact me if you need to send any information to John. Thank you for your understanding."

Whom to call: Unless you have been told otherwise, you need to notify your Supervisor or someone in the Personnel Department or Human Resources Department about any unplanned absence.



Here are some additional ideas to keep your job on track:

BE PROACTIVE! Find out what your employer’s policies are concerning employee absences and Medical Leave, including finding out about the Family Medical Leave Act, a law designed to protect workers and family members who have illnesses. That way you will know exactly what to do if you ever need to miss work due to a mental health crisis or for any other reason. You can record work-related information below.

- ◆ In larger companies or organizations, you can get this information from the Human Resources Department and/or a company manual.
- ◆ In smaller companies, ask the owner or manager how they handle absences and how you can keep your job if you are out sick for a while. If possible, get it in writing!
- ◆ You know that it’s much easier to find out what you need to know when you are feeling well than when you are feeling ill. So try to collect the necessary information as soon as possible!



Get information from your doctor:

- ◆ If possible, try to get some idea from your doctor about how long you can expect to be away from work.
- ◆ Your employer will probably require a doctor’s note if you are away from work for three or more days, so write a reminder in your plan to get one if necessary.

Below is an example of contact information you might want to record in your ASAP so that it is readily available if you ever need it. You can also make notes about your employer’s policies in the space below and/or attach them to this section of your guidebook.

EXAMPLE: _____

Company: _____

Name of Supervisor: _____

Work Phone: _____

Personnel or Human Resources Dept. Phone #: _____

Personnel Director: _____

Notes: _____

KEEPING YOUR EDUCATION ON TRACK

Notify your school about your absence as soon as possible. If you are registered with your school's **Office of Disability**, that is the first place you should call. They can give you information about how to proceed. Otherwise, call the **Counseling Office** first and ask them how to proceed.

GREAT IDEA!



BE PROACTIVE! It's a good idea to obtain information about how an extended absence will affect your student status **BEFORE** it happens! That way you will know exactly what to do if you ever need to miss school due to a mental health crisis or for any other reason.

GREAT IDEA!



Get information from your doctor:

- ◆ If possible, try to get some idea from your doctor about how long you can expect to be away from school.
- ◆ Your training or academic institution might require a doctor's note if you miss many classes, so find out if you need one and be sure to include in your plan how to get one if necessary.

Your ASAP provides a place to list contact information for school-related matters. It's also good to get answers to the questions on the next page; put this information into your ASAP document and/or directly into this guide.

EXAMPLE: _____

Name of School: _____

School's Main Phone: _____

Name of Your Counselor: _____

Counseling Office Phone: _____

Office of Disability Phone: _____

Financial Assistance/Loan/Grant/Scholarship Office Phone: _____

Other Important Phone Numbers: _____

In the event that you might be away from school for an extended period of time, it's important to ask the following questions and know how these issues will be handled. You can record the necessary information in the spaces below.

What is my school's policy about medical leave? How will an extended leave affect my student status?

How does my school handle courses that I am not able to complete within a semester ("incompletes")? Will I have to pay for courses again if I am not able to complete them?

How will an extended absence affect the terms of my financial aid, such as my loan, grant or scholarship?

- ADDITIONAL NOTES -

We hope that this Guidebook has helped you organize your thoughts about advance planning. You are now ready to create your own Advance Self-Advocacy Plan... A.S.A.P.!

PLANNING SUPPORT MATERIALS

TIPS: Some things to keep in mind while creating your ASAP:

- ◆ Work on your plan (or parts of your plan) when you are feeling fairly well.
- ◆ You do not need to complete every section of the plan in order for it to be useful. However, you want to make sure that you fill out information for those areas that are most important to you. You can cross out anything that you do not want included on your plan and initial this area.
- ◆ Think carefully about the information you include and perhaps discuss your choices and decisions with people who can contribute to the plan that you create. Be as specific as you can when writing down your preferences so that others will know exactly what you want.
- ◆ If it's helpful, make use of Plan Contributors: If you need help thinking about or getting information for your plan, you can ask your **Plan Assistant(s)**, **Plan Supporter(s)** and **Mental Health Professionals** to assist you.
- ◆ **Don't be discouraged if you don't have all the information at your fingertips...** write down whatever you DO know and make a note of what you need to find out. You can use the ASAP **"Find It" Sheet** located at the end of the guidebook to keep track of the information you need to find and add to your ASAP.

- ADDITIONAL RESOURCES -

National Resource Center on Psychiatric Advance Directives:

<http://www.nrc-pad.org/index.php>

Bazon Center for Mental Health Law (Template/Forms for completion, FAQs):

<http://www.bazon.org/issues/advancedirectives/index.htm>

Mental Health America (formerly National Mental Health Association) Psychiatric Advance Directive Toolkit:

<http://www1.nmha.org/position/advancedirectives/index.cfm>

The Advocacy Center for Persons with Disabilities (PAD Toolkit):

<http://www.advocacycenter.org/AdvanceDirectives/advancedirectives.htm>

National Disabilities Rights Network:

<http://www.napas.org/issues/advdir/default.htm>



Emergency Contacts Cards / ASAP Support People

Please contact the following people to assist me with the indicated items if I am temporarily unable to care for them myself:

Name: _____ Relationship: _____ Phone Numbers: Home: _____ and/or Cell # _____ Work # _____ Address: _____ Type of assistance requested: _____	Name: _____ Relationship: _____ Phone Numbers: Home: _____ and/or Cell # _____ Work # _____ Address: _____ Type of assistance requested: _____
Name: _____ Relationship: _____ Phone Numbers: Home: _____ and/or Cell # _____ Work # _____ Address: _____ Type of assistance requested: _____	Name: _____ Relationship: _____ Phone Numbers: Home: _____ and/or Cell # _____ Work # _____ Address: _____ Type of assistance requested: _____

