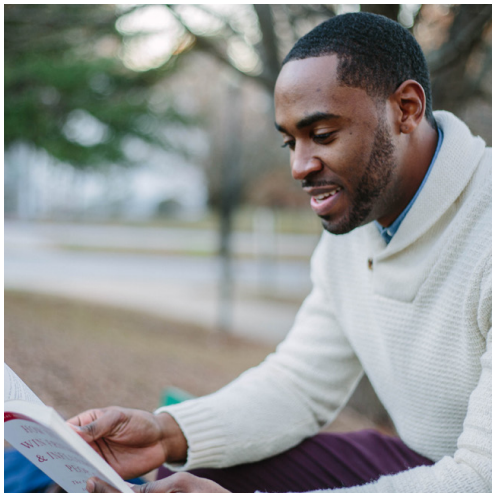


2019 FAMILY CAREGIVERS TOOLKIT



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MHIA
Mental Health America

INTRODUCTION

Over 100 years ago, our founder, Clifford W. Beers vowed to “fight in the open” for the rights of individuals living with mental illness. As an individual living with manic depression, he received a lot of support from his brother and in turn gave a lot of support to members of his family throughout his recovery.

Today, we continue to focus on the rights of individuals with mental illness and recognize the role that family members and loved ones play in recovery.

Mental Health America (MHA) is proud to recognize November as National Family Caregivers Month - a time to celebrate the contributions of caregivers, provide them with tools that they need, and continue to advocate for individuals with mental illness.

While it's important for people with mental illnesses to have a voice and be involved in their own recovery, it's equally important as caregivers to check in with their own mental health.

Since 2014, MHA has screened over 250,000 caregivers for mental health conditions at mhascreening.org. Over three-fourths of caregivers showed moderate or severe symptoms of a mental health condition.

MHA has developed its 2019 National Family Caregivers Month toolkit to help educate and empower caregivers as they strengthen relationships with their loved ones with mental illness.

With the right tools and perspectives, caregivers and their loved ones can work together as a team to accomplish goals, find a treatment plan that works, be prepared in the event of a crisis and work to move along the path to recovery.

Please join us and fight in the open to create an inclusive world for caregivers and their loved ones to thrive [#together4mentalhealth](https://twitter.com/together4mentalhealth).

This year's toolkit includes:

- Key Messages
- Drop-In Article
- Sample Social Media Post Language
- Social Media Images for Sharing
- Additional Resources
- Fact Sheet: Setting Goals for Recovery
- Fact Sheet: HIPAA: What are a Caregiver's Rights?
- Fact Sheet: New Treatment Options
- Fact Sheet: Talking to Treatment Providers
- Fact Sheet: Treatment Supports
- Poster (Landscape Orientation)
- Poster (Portrait Orientation)
- Be Prepared: Crisis Plan Worksheet

QUESTIONS?

If you have further questions, please contact Danielle Fritze, Associate Vice President of Public Education and Design at dfritze@mhanational.org.

KEY MESSAGES

- Mental Health America has developed its 2019 National Family Caregivers Month toolkit to help caregivers strengthen relationships with their loved ones with mental illness through materials that educate and empower.
- Recovery is not one size fits all and what works for one person might not work for another. It makes sense that caregiving would not look the same for everyone either.
- While no two caregiver relationships are alike, there are some things we know are essential to everyone's recovery.
- Having a plan in place can help a caregiver make sure they set their loved one up to thrive throughout the recovery process - and can ensure that their voice is heard in the event of a crisis.
- With the right tools and perspectives, caregivers and their loved ones can work together as a team to accomplish goals, find a treatment plan that works and be prepared in the event of a crisis.
- It's important for people with mental illnesses to have a voice and be involved in their own recovery. Caregivers should ask their loved one what they want and need and include them in any decisions being made.
- Working towards established goals helps people in recovery stay motivated and hopeful.
- People with mental health conditions are often left out of mainstream activities like employment or education, but they have the right to meaningfully contribute to their community and be respected just like everyone else, peer support can help.
- By staying educated on the latest treatment options, caregivers can help their loved one make informed decisions about their treatment.
- Caregivers are more likely to experience stress, that is why it is important for them to take care of their own mental health.
- When we take the time to invest in our mental health, we can focus on creating an inclusive world for caregivers and their loved ones to thrive, together.

Feel free to supplement these key messages with language from the fact sheets and other materials included in this toolkit.

DROP IN ARTICLE

Use this article in your next e-blast or submit to your local newspaper.

So often people with mental illnesses are being cared for by family members or close friends. It can be a complex and complicated relationship that can be challenging - for both the individual dealing with the illness and their caregiver to navigate.

Recovery from a mental illness is not one-size-fits-all and what works for one person might not work for another. Just as recovery looks different for everyone, so do relationships between caregivers and their loved ones with mental illness. You may be a spouse caring for your partner or a young person caring for your parent; caregivers vary across the board in their roles, resources and abilities to support someone in recovery. While no two caregiver relationships are alike, there are some things we know are essential to everyone's recovery.

This November is *National Family Caregivers Month* and [ORGANIZATION NAME] is sharing tools to help caregivers strengthen relationships with their loved ones with mental illness through materials that educate and empower. If you are a caregiver, with the right tools and perspectives you can work together with your loved one as a team to accomplish goals, find a treatment plan that works, and be prepared in the event of a crisis.

It's important for people with mental illnesses to have a voice and be involved in their own recovery. As a caregiver, it is vital to work with your loved one to determine what they want and need - and make sure they are included in any decisions being made. People with mental health conditions are often left out of mainstream activities like employment or education, but they have the right to meaningfully contribute to their community and be respected, just like everyone else. Peer support can help and teach skills so your loved one may keep working towards established goals that help people in recovery stay motivated and hopeful.

By staying educated on the latest treatment options, you can help your loved one make informed decisions about their treatment. Having a plan in place can help you make sure you set your loved one up to thrive throughout the recovery process - and can ensure that their voice is heard in the event of a crisis. But caregiving can be extremely stressful, that is why it is important for you to also take care of your own mental health. Visit mhascreening.org to take a free, anonymous, and confidential screen.

[ORGANIZATION] wants everyone to know that when we take the time to invest in our mental health, we can focus on creating an inclusive world for caregivers and those with mental illness to thrive, together.

Find out more and download the toolkit at mhanational.org/national-family-caregivers-month.

SAMPLE SOCIAL MEDIA POSTS

Hashtags: #together4mentalhealth, #FamilyCaregiversMonth

- November is #FamilyCaregiversMonth! Mental Health America developed a toolkit to help caregivers strengthen relationships with their loved ones with mental illness through materials that educate and empower. Learn more: [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver) #together4mentalhealth
- November is #FamilyCaregiversMonth! In the US, over 65 million unpaid #caregivers support a loved one who is disabled, ill, or aged – including those with #mentalhealth conditions. Working #together4mentalhealth is critical in the recovery journey. Learn more: [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver)
- With the right tools and perspectives, caregivers and their loved ones can work #together4mentalhealth as a team to accomplish goals, find a treatment plan that works and be prepared for a crisis. Learn more this November for #FamilyCaregiversMonth: [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver)
- Having a plan can help a caregiver set their loved one up to thrive throughout the #recovery process - and can ensure that their voice is heard in the event of a crisis. Learn how to work #together4mentalhealth with our new #caregivers toolkit: [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver) #FamilyCaregiversMonth
- Learn more about working #together4mentalhealth for #FamilyCaregiversMonth: [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver)
- People with mental illnesses should have a voice in their own #recovery. Caregivers should ask what they want and need and include them in decisions being made. Learn more about how you can work #together4mentalhealth with our new toolkit!: [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver) #FamilyCaregiversMonth
- What is HIPAA and what should caregivers of individuals with mental health conditions know about their rights? Learn more in our #caregivers toolkit: [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver) #FamilyCaregiversMonth #together4mentalhealth
- “What if I think my loved one is incapable of making health decisions?” For #FamilyCaregiversMonth, we go over questions from #caregivers like this and more in our newest toolkit. Learn more and download the toolkit at [\[bit.ly/mhcaregiver\]](https://bit.ly/mhcaregiver) #together4mentalhealth

IMAGES

Download and save the images provided for use on your social media platforms or websites. All images can be downloaded by visiting <https://mhanational.org/download-2019-family-caregivers-toolkit>, then right-clicking on the image and selecting "Save image as."



ADDITIONAL RESOURCES

General Caregiving

[CaregiverAction.org](https://www.caregiveraction.org) - Education, peer support, and resources for family caregivers.

[ChoicesInRecovery.com](https://www.choicesinrecovery.com) - Support and information for people with Schizophrenia, Schizoaffective, and Bipolar Disorder and their caregivers, including resources for having conversations with treatment professionals.

[MoreThanMyDiagnosis.com](https://www.morethanmydiagnosis.com) - Stories and advice from people who either live with mental health issues or care for someone who does.

Treatment Supports

[MHAnational.org/find-affiliate](https://mhanational.org/find-affiliate) - Find your local MHA affiliate and see what peer support programs are offered or get connected with local health and wellness programs.

[AskJAN.org](https://www.askjan.org) – The Job Accommodation Network’s official website with resources for individuals, employers, and others surrounding workplace accommodations and disability employment issues. Also, in Spanish.

[Clubhouse-Intl.org](https://www.clubhouse-intl.org) - A website for individuals living with mental illnesses to find Clubhouses—safe environments with opportunities for friendship, employment, housing, education and access to medical and psychiatric services in a single setting.

[HUD.gov](https://www.hud.gov) – The U.S. Department of Housing and Urban Development website helps you find rental help and get connected to local housing resources in your area.

[Inspire.com](https://www.inspire.com) - A social network for patients and caregivers to connect, share, and learn from each other about medical conditions, treatment, and support.

[TheMighty.com](https://www.themighty.com) - A safe, supportive online community for people facing health challenges and the people who care for them.

HIPAA and Privacy

[HHS.gov/hipaa/for-individuals/mental-health](https://www.hhs.gov/hipaa/for-individuals/mental-health) - A page on Health and Human Services website with information about the HIPAA Privacy Rule directly related to mental health and substance use disorders with resources for individuals, parents, families and more.

[NRC-PAD.org](https://www.nrc-pad.org) - The National Resource Center on Psychiatric Advance Directives website has resources to walk you through creating a psychiatric advance directive - including state by state information, FAQ’s and more.



SETTING GOALS FOR RECOVERY

THE GOAL SETTING PROCESS IS ABOUT HELPING YOUR LOVED ONE THINK ABOUT WHAT IS IMPORTANT TO THEM AND DEVELOPING A VISION OF WHAT THEY WOULD LIKE THEIR LIFE TO BE. RESEARCH SHOWS THAT WORKING TOWARDS ESTABLISHED GOALS PROMOTES HOPE AND ENHANCES MOTIVATION.¹

WHAT ARE RECOVERY GOALS?

Recovery goals are objectives that a person sets that are related directly to their recovery (mental health-based goals), and that may have been put on pause due to their mental health condition (work, family, physical health, social life, etc.) Recovery is not one size fits all. It is important to have a discussion with your loved one about what is most important for them. For instance, one person's goal may be to live independently once they have reached a certain point in their recovery, while another person may be content to live with a roommate or caregiver.

It is important to remember that you are not there to do the work for your loved one as a caregiver. Goal setting should be a collaborative process as you assist your loved one through setting specific and challenging, yet attainable, goals. Once goals have been set, being supportive and encouraging of the choices that your loved one has made can help them stay on a path to recovery.

CAREGIVER TIPS FOR GOAL SETTING

When trying to help your loved one come up with goals, think about the steps they will have to take in order to achieve their long-term objectives. Consider smaller actions and short-term goals that could be related or require the same skill set—anything you can think of that is realistic for the *now*. For example, if your loved one has indicated that receiving their GED is a long-term goal, suggest they start reading 30 pages per day of material from a topic that interests them and go from there. Furthermore, finding a topic that interests them may be a short-term goal in itself.

FINDING OUT WHAT IS IMPORTANT TO YOUR LOVED ONE MAY BE DIFFICULT AT FIRST. HERE ARE SOME EXAMPLE QUESTIONS TO GET THE CONVERSATION GOING:

- > What would you like to be different about your current situation?
- > What do you like about your life now?
- > What is your greatest achievement?
- > What do you miss about your life before recovery?
- > What makes you feel better, if only for a second?
- > What do you hope to be doing one year from now?

BEING SUPPORTIVE

Here are some tips for being a supportive caregiver during the goal setting process.

- > **Do it together.** Find out what is important to your loved one and ask questions. Revisit what may have been put on hold because of their condition - such as their employment status, social or family life, dreams or aspirations. To get down to the core of a goal and make it more engaging and exciting, ask follow-up questions about what it would mean for them. The more you know, the better you can help them arrive at goals that are meaningful.
- > **Set short- and long-term goals.** For a person recovering from mental illness—especially when they are beginning treatment—the idea that their life could someday be different may seem out of reach. Achieving smaller, more immediate, measurable, and realistic goals can help generate momentum in the recovery process. Goals like getting out of bed at a certain time can help one stay motivated and focused so that they are able to work towards long-term goals, such as reconnecting with family.
- > **Keep your loved-one accountable.** Caregivers can support ongoing and long-term goals by holding their loved one accountable through tracking goals and celebrating progress along the way. Gentle check-ins can be useful to monitor progress. It is important not to make the loved one feel guilty if they are not reaching goals as quickly as anticipated, however. This can make the process more difficult, potentially prompting the person in recovery to be untruthful about their recovery progress.
- > **Be flexible.** The road to recovery is not linear. At times it may feel like your loved one is taking one step forward and two steps back, but even slow progress is progress. Priorities change, life happens, and you may have to make some adjustments along the way. Periodically revisit goals to ensure that the benchmarks you are focusing on still fit your loved ones needs and values at the time.
- > **Remember your place.** The ultimate goal of being a caregiver is to help your loved one experience recovery. They will be most successful in their recovery when they have a degree of control and are actively involved in the process. This fosters the self-determination and independence needed for sustainable recovery.
- > **Be prepared for times of crisis.** Part of your discussion around your loved one's needs should focus on what happens when they are in crisis so that you are prepared to move forward together when you are the only person to act on their behalf. If you must make decisions for your loved one or act without involving them, it should only be done as temporary crisis management. Once they have stabilized, you should help return them to pursuing their recovery goals.

CARING FOR YOURSELF IS AN IMPORTANT PART OF BEING A CAREGIVER

Did you know that caregivers tend to experience higher levels of stress² and frustration³ than those who are not caregivers?



Being a caregiver can be hard, so it's important to check in on your own mental health from time to time.

Visit mhascreening.org to take a free, anonymous, and confidential screen.

SOURCES

¹Clarke, S. P., Oades, L. G., Crowe, T. P., & Deane, F. P. (2006). Collaborative Goal Technology: Theory and Practice. *Psychiatric Rehabilitation Journal*, 30(2), 129-136. <http://dx.doi.org/10.2975/30.2006.129.136>

²Pinquart, M. & Sorensen, S. (2003) Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, 18(2), 250-267.

³Center on Aging Society. (2005). *How Do Family Caregivers Fare? A Closer Look at Their Experiences*. (Data Profile, Number 3). Washington, DC: Georgetown University.



HIPAA: WHAT ARE A CAREGIVER'S RIGHTS?

WHEN YOUR LOVED ONE IS EXPERIENCING A MENTAL HEALTH CRISIS, IT CAN BE HARD TO KNOW WHAT TO DO. YOU ARE CONCERNED ABOUT THEIR WELL-BEING, WANT TO KNOW WHAT IS GOING ON AND MAY WANT TO COMMUNICATE WITH THEIR HEALTH CARE PROVIDERS. SOMETIMES IT CAN FEEL LIKE HIPAA AND PRIVACY RULES ARE KEEPING YOUR LOVED ONE FROM EFFECTIVE TREATMENT RATHER THAN HELPING THEM RECEIVE IT. HOWEVER, HIPAA'S RULES AND REQUIREMENTS ARE OFTEN MISUNDERSTOOD, AND IT IS IMPORTANT FOR CAREGIVERS TO BE INFORMED OF THE RIGHTS THEY DO HAVE.

WHAT IS HIPAA?¹

The Health Insurance Portability and Accountability Act (HIPAA) sets federal standards for privacy of protected health information and medical records. HIPAA protects individuals against the release of their medical records and other identifiable health information and balances it with a provider's ability to act when information is needed for treatment and other appropriate purposes. HIPAA also deals with things like insurance companies and hospitals.

When it comes to the privacy provisions, HIPAA does things like prevents people from "outing" someone for their mental health condition or seeing a therapist to the public, or from providers snooping in medical records. As a caregiver, you may find it frustrating if you're trying to find a loved one or share information. But you and others who care about your loved one may have more rights than you realize under HIPAA.

A central part of HIPAA is that personal health information and medical records are only allowed to be released through written authorization which is consent from an individual that allows a provider to use or disclose their personal health information.

WHAT IS HIPAA?

Protected health information (PHI) is any medical record that ties back to your identity. It includes your personal past, present, and future health care that is created, stored, or passed on by a health care provider. This includes information on specific illnesses, what treatment you received, your goals and your outcomes. Other information is included in your medical record such as demographic information. Demographic information includes your name, address, social security number, and even family history and current support systems. In mental health, PHI can include information that you gave a provider to help provide better care. This type of information includes information like trauma history or other medical conditions.

Certain types of information receive special treatment and are not included in general HIPAA authorizations.

Psychotherapy notes² are notes taken by a clinician documenting or analyzing a conversation during a private therapy session. HIPAA requires a separate authorization to discuss these details, although information for billing and appointments are governed by general HIPAA and your therapist can pass on information about

conversations to your insurance provider to make sure you get covered for care by insurance.

Substance use records are also treated differently than medical records under 42 CFR Part 2,³ a privacy law that protects a person's substance use disorder information and require an additional authorization on top of the HIPAA authorization. Another regulation, the Family Educational Rights and Privacy Act (FERPA), provides additional protections for students.

WHO GETS ACCESS TO WHAT INFORMATION?

Under HIPAA, personal health information and medical records are only allowed to be released through written authorization. Only the individual has full access to review and make decisions on what to do with your information. If you are helping someone with their care, the time to make sure you receive authorization is done best at intake. During intake, work with your family member to include you as an individual that can receive their PHI, talk to their provider, and help them navigate their health care decisions. Without authorization a doctor is not allowed to speak to a family member and will not even tell you if they are treating your loved one at that facility.

Use the chart below to find out more information about different types of authorizations required under HIPAA.^{4,5,6,7,8}

GROUP	WHAT INFORMATION CAN BE ACCESSED AND WHEN?
Adults with a mental health condition or substance use disorder condition (18+)	Individuals have full access to their medical records and personal health information. They may ask to see or get a copy of their information, change any incorrect information, decide where to send copies of health information, and sign authorization forms for release.
Minors with a mental health condition or substance use disorder	Minors under the age of majority, which is 18 in most states, cannot legally exercise their HIPAA privacy rights. The general rule is that parents or guardian should be treated as a personal representative and thus have access to medical records and personal health information. State laws and circumstances vary.
Personal Representative: Adults can name a personal representative of their choosing, which would give that person power of attorney over health care decisions.	Personal representatives can access all their loved one's health information (except psychotherapy notes), decide where to send copies of their information, and have the same rights to privacy as their loved one concerning their health information. A personal representative is someone who has access because they are considered a health care power of attorney or executors of estates.
Legal Guardian of a minor: In most states, a minor under HIPAA refers to a person under the age of 18 who is not emancipated either through marriage or court order. State law may affect this process so check with your state to verify. Generally, parents or whomever has the legal authority to make health care decisions for a minor is their personal representative although special circumstances apply. HIPAA does leave rules in place for parents who are not the legal guardians of their children, and you may be allowed access to information depending on your state's laws. Contact your local MHA affiliate for more information at https://arc.mhanational.org/find-affiliate .	Legal guardians of minors have the same right to access medical records and personal health information as a personal representative. They may ask to see or get a copy of the minor's information, change any incorrect information, decide where to send copies of health information, and sign authorization forms for release.
Family member or friend	Family and friends may receive health information if their loved one agrees to release information and signs an authorization. This process is best completed during admission to a medical facility or prior to a doctor appointment. If you are involved in their health care and help your loved one with making appointments, housing, companionship, transportation, supervision or other tasks, a provider can share information related to your involvement in your loved one's care-if they agree or do not object.

FREQUENTLY ASKED QUESTIONS

> WHAT IF I THINK MY LOVED ONE IS INCAPABLE OF MAKING HEALTH DECISIONS?

Sometimes when a loved one is experiencing a mental health crisis, they may become very sick and lack the capacity to make informed decisions. HIPAA allows mental health clinicians to use their professional judgment to determine what is in the best interest of an individual and decide whether and to whom they release information to.

> WHEN CAN INFORMATION BE DENIED?

If at any point a provider has concerns about the well-being of an individual or is worried that the person requesting information may not be acting in your loved one's best interest, they can decide to recognize or not recognize them as the person's personal representative and deny access to all health information. The same goes for minors; if a provider has concerns about parental abuse, neglect or endangerment, it is up to the provider to make the decision.

> WHAT IF I AM NOT INVOLVED IN CARE BUT AM STILL CONCERNED ABOUT A LOVED ONE?

If you are not involved with the health care or payment for care of your loved one, a provider can share information with you if they need help contacting family, friends or caregivers and you can provide general directory information if your loved one does not object.

Regardless of who you are, a provider can share information with you if needed to prevent harm or lessen a threat to your loved one or others, using their discretion.

> HOW DO I TALK TO MY LOVED ONE ABOUT GETTING ACCESS TO THEIR INFORMATION?

Let your loved one know the reasons why you would like to see their information. Explain how it can help both of you. Let them know that you respect their privacy but just want to be as supportive as possible. Talk to them about creating a crisis plan and learn more about psychiatric advance directives below.

> WHY DOESN'T MY LOVED ONE WANT TO GIVE ME ACCESS TO THEIR INFORMATION?

There are many reasons your loved one may not want their information shared. Perhaps your loved one may have shared details about family or be dealing with very private subjects like abuse. Or they are worried the information will be used against them and deal with a lot of shame or sometimes strained relationships may get in the way. There may not be any one answer or an answer at all – some people just prefer to be private. If your loved one does not give you access to their information, it is their choice and you should try and respect that - but remember, it doesn't make you any less valuable as a caregiver.

THINGS TO REMEMBER

HIPAA doesn't prevent a provider from listening to what caregivers have to say. If the provider or facility is saying that they can't "speak" with the caregiver due to their rules, or if permission from the patient is denied, providers may still listen to information provided by caregivers. HIPAA does not in any way prevent a provider from receiving information from a caregiver regarding the person's history, previous treatment, or recent symptoms. This means that if you are concerned about your loved one and have information that may be helpful for their care team to know, the provider can still listen to that information and you can help make sure the doctor has the full picture.

A VALUABLE TOOL

An underutilized and lesser-known action that is available is creating a psychiatric advance directive. This is a lifesaving tool that can help assure better outcomes. Similar to a medical advance directive or a health care power of attorney, a psychiatric advance directive is a legal document completed in a time of wellness by an individual that provides instructions regarding treatment or services one wishes to have - or not have - during a mental health crisis. Should your loved one experiencing mental health crisis become too sick to make decisions, their psychiatric advance directive takes effect and ensures their desires may be communicated clearly to their care team. Learn more at <https://www.mhanational.org/psychiatric-advance-directive>.

SOURCES

¹<https://www.hhs.gov/sites/default/files/hipaa-helps-prevent-harm.pdf>

²<https://psychcentral.com/lib/psychotherapy-notes-and-hipaa>

³<https://iac.org/addiction-confidentiality-42-cfr-part-2-important>

⁴<https://www.hhs.gov/hipaa/for-individuals/guidance-materials-for-consumers/index.html>

⁵<https://www.hipaahelpcenter.com/privacy/how-does-hipaa-privacy-rule-apply-to-minors>

⁶<https://www.hhs.gov/sites/default/files/families-hipaa-decision-tree-adult-patients.pdf>

⁷<https://www.hhs.gov/sites/default/files/am-i-my-childs.pdf>

⁸<https://www.hhs.gov/sites/default/files/minors-hipaa-decision-tool.pdf>

CARING FOR YOURSELF IS AN IMPORTANT PART OF BEING A CAREGIVER

Being a caregiver can be hard, so it's important to check in on your own mental health from time to time.

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NEW TREATMENT OPTIONS

FOR MOST PEOPLE LIVING WITH MENTAL ILLNESSES, A COMBINATION OF THERAPY AND MEDICATION IS THE MOST EFFECTIVE FORM OF TREATMENT. MANY MEDICATIONS HAVE BEEN AVAILABLE FOR DECADES AND HAVE PROVEN TO BE HELPFUL FOR MILLIONS OF PEOPLE, HOWEVER WHEN “TRADITIONAL” MEDICATIONS ARE NOT WORKING FOR YOUR LOVED ONE, IT MAY BE TIME TO LOOK AT OTHER OPTIONS. AS BEHAVIORAL MEDICINE CONTINUES TO ADVANCE, NEW TREATMENT OPTIONS CAN OFFER MORE FREEDOM AND FLEXIBILITY TO THOSE SEEKING HELP.

NEARLY 1/3

**OF PEOPLE WHO
ARE TREATED FOR
DEPRESSION DON'T
EXPERIENCE RELIEF
FROM “TRADITIONAL”
TREATMENTS¹**

WHAT MAKES A MEDICATION “NEW”?

New medications may act on a different set of chemicals or chemical receptors in the body or brain to treat a condition or may be a different formula of medication that targets the same chemicals or chemical receptors as other existing treatments. When a new medication is approved by the FDA, it does not always mean that the drug itself is new, it may just be newly available in a different format (i.e. a daily pill is now available as an injection that lasts weeks).

CAN MY LOVED ONE TRY NEW TREATMENTS RIGHT NOW?

Because newer medications are often more expensive, they may not be covered by insurance or may only be covered under certain circumstances. Before prescribing one of these newer treatments, providers will likely try to adjust “traditional medications” for a patient in several ways. This may mean giving a medication more time to take effect, increasing dosage, adding another type of medication to better control symptoms or side effects, and/or switching to a different family of medications used to treat the same condition. In the case of treatment-resistant depression, a person will have to have tried at least two antidepressants without success before they will be considered for the newest type of medication.

WHAT NEW TREATMENTS ARE AVAILABLE?

In the last 5 years, seven new medications have been approved by the FDA for treatment of mental health conditions.²

DRUG NAME	USE	HOW IT'S TAKEN
Aripiprazole lauroxil (Aristada)	Schizophrenia	Muscle Injection
Brexanolone (Zulresso)	Postpartum Depression	IV Infusion
Brexiprazole (Rexulti)	Depression & Schizophrenia	Pill
Cariprazine (Vraylar)	Bipolar Disorder & Schizophrenia	Pill
Esketamine (Spravato)	Treatment-Resistant Depression	Nasal Spray
Paliperidone Palmitate (Invega Trinza)	Schizophrenia & Schizoaffective Disorder	Muscle Injection
Pimavanserin (Nuplazid)	Parkinson's Disease Psychosis	Pill

WEIGHING THE PROS AND CONS

New medications may offer a variety of benefits to those who take them. For instance, some medications may be fast-acting and provide symptom relief in a matter of days rather than weeks, others may be long-acting and do not need to be taken on a daily basis, making it easier to stick to a treatment plan. Others may have fewer or less severe side effects than their older counterparts. However, new medications just like all medications, may have their drawbacks. Some have to be taken at the doctor's office, which can be difficult for people with strict job schedules or transportation issues. An individual may not tolerate a medication well, or a new medication may have serious interactions with prescriptions taken for other health conditions. It is always best to discuss any medication changes with your loved one's treatment provider and pharmacist.

Additionally, new treatments may be very expensive or not be covered by insurance. If your loved one has been prescribed a new medication, but you are having trouble affording their care, there are prescription assistance programs available to help cover costs. Often these programs are available from the companies that produce the medications themselves.

ALMOST 1/2
OF PEOPLE WITH
SCHIZOPHRENIA DO
NOT STICK WITH THEIR
MEDICATION PLAN³

SOURCES

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CLINICAL TRIALS

Another option for individuals who haven't found relief is to participate in a clinical trial. Treatment trials may explore combining existing medications in new ways, testing medicines that are still in development, or using medical procedures or devices to reduce symptoms. While they are designed to be as safe as possible, there is a very real risk that a person could have medical complications while participating in an experimental treatment trial. To learn more about the process of participating in a clinical trial, visit www.nih.gov/health-information/nih-clinical-research-trials-you.

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Did you know that caregivers tend to experience higher levels of stress⁴ and frustration⁵ than those who are not caregivers?



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TALKING TO TREATMENT PROVIDERS

TREATMENT DECISIONS ARE BEST MADE WHEN ALL PARTIES INVOLVED CAN COMMUNICATE CLEARLY AND OPENLY WITH ONE ANOTHER; CAREGIVERS CAN HELP ENSURE OPEN LINES OF COMMUNICATION DURING APPOINTMENTS BY HELPING THEIR LOVED ONE PREPARE BEFOREHAND. IT IS IMPORTANT FOR INDIVIDUALS RECOVERING FROM A MENTAL ILLNESS TO HAVE A SAY IN THE CARE THEY ARE RECEIVING. BUT IT CAN BE HARD FOR YOUR LOVED ONE TO REMEMBER EVERYTHING THEY WANT TO SAY TO THEIR CARE PROVIDER DURING A VISIT; THAT IS WHY IT IS ALWAYS A GOOD IDEA TO PREPARE IN ADVANCE OF AN APPOINTMENT.

PEOPLE WITH SERIOUS MENTAL ILLNESS ARE MORE LIKELY TO EXPERIENCE A HOST OF CHRONIC PHYSICAL CONDITIONS.²

How much a person feels involved in their own treatment has been positively associated with satisfaction and empowerment during recovery.¹ By talking with your loved one beforehand and helping them come up with a list of symptoms, side effects, concerns and questions they may have, you can help ensure your loved one gets the most out of the valuable time spent with their care provider.

TIPS FOR MAKING THE MOST OUT OF APPOINTMENTS

- > **Talk to your loved one.** Individuals vary in what is most helpful to them. Start by asking your loved one about whether they need or even want help. Your loved one may need you to take the lead in the doctor office or they may just want you in the room for moral support. Never assume you know what they want - always ask.
- > **Make lists.** Before the appointment, outline all the topics your loved one wants to discuss, to ensure you use your time wisely and nothing is left out. Start by making a list of any current side effects, symptoms or concerns your loved one may be experiencing. Encourage them to review any mood tracking materials or journals. If they are seeing a new provider, consider listing some specifics about their condition, like triggers. Any information you can provide that will help paint a clearer picture about your loved one and their condition is helpful. Getting your loved one to talk about these things may not be easy at first. Here are some example questions to help those conversations:
 - What symptoms are you currently experiencing? Which of these symptoms do you find to be the most challenging?
 - Overall, do you feel better, worse or about the same since the last appointment?
 - How well do you think your medications are working?
 - Do you have any challenges with your medication(s), like negative side effects?
 - Are there any concerns you would like to talk about?
 - Have you noticed anything different physically with your body?
- > **Address physical health.** Get an update on your loved one's physical health; make a list of any changes to treatment, new medications or ailments. See what physical side effects they might be experiencing. Doctors need to know about any medications your loved one may be taking for other conditions; it helps them avoid prescribing anything that could interact negatively. Update the provider about any changes.

> **Prepare questions.** Time moves quickly during appointments, so it may be helpful to prepare questions ahead of time to find out information, strengthen communication and ensure all concerns are addressed. Encourage your loved one to make their own list of questions. Here are some ideas:

- If starting or considering a new treatment option – ask what exactly the medicine is supposed to do, what side effects it may cause and for how long, how long it will take to work, what to do if you skip a dose, and how much it costs.
- If a treatment isn't working or the side effects outweigh the benefits your loved one is receiving, ask about other treatment options.
- Ask about the benefits and risks of different treatments.

> **Take notes.** Be sure and write down any important information you learn during the appointment, including answers to your questions or anything you and your loved one may want to learn more about. You can ask your provider about suggestions for additional reading, especially regarding new treatments. Don't be afraid to explicitly ask the provider why something is being prescribed, what the treatment is supposed to do, and which symptoms it will address - and remember to write it down. Before the next appointment, review your notes and check in with your loved one to see if their treatment plan is working.

> **Let your loved one do the talking.** One of your responsibilities as a caregiver is to help foster independence. Make sure you let your loved one do all the talking they are willing and able to do and use the list you have made to help them address their questions and concerns. You are there to support communication between the provider and your loved one. Step in only when needed and be attentive to what your loved one is saying verbally and nonverbally during the appointment.

> **Maintain communication.** Lots of time can pass between appointments. As your loved one moves forward with adjustments to their treatment, you may be able to notice changes that your loved one may not pick up on. Talk with them and share your thoughts. Throughout this process you can help your loved one by making note of information regarding their symptoms, side effects and concerns as they bring them up. When it is time for your next appointment, you can compile your notes and make a new list.

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TREATMENT SUPPORTS

IT IS EASY TO GET CAUGHT UP WITH MEDICATION AND THERAPY APPOINTMENTS, BUT MOST PEOPLE DO NOT RECOVER THROUGH ANY ONE ACTION ALONE. A BALANCED MIND STILL NEEDS OPPORTUNITIES TO PRACTICE SKILLS LEARNED IN THERAPY THROUGH MEANINGFUL INTERACTIONS WITH THE WORLD AROUND THEM. RECOVERY IS BEST ACHIEVED WHEN A FULL TREATMENT PLAN PROMOTES INCLUSION AND CONNECTION THROUGH COMMUNITY INVOLVEMENT AND PEER SUPPORT. TALK WITH YOUR LOVED ONE AND HELP THEM DETERMINE HOW THEY WOULD LIKE TO ENGAGE WITH THOSE AROUND THEM.

COMMUNITY INCLUSION

Community inclusion is increasingly being recognized as one of the most important concepts for fostering and assessing the recovery of people with mental illness.¹ Studies show that re-connection with society promotes recovery and decreases the chance of relapse.²

Community inclusion means that all people, regardless of their health care needs, have the right to be respected as members of their communities. Those with mental illness, just like everyone else, should have the right to participate in recreational activities in neighborhood settings, work at jobs in the community that pay a competitive wage, explore and use their skills and abilities to the fullest, and pursue educational opportunities with their peers.

People with mental illnesses face a lack of community inclusion made worse by common hinderances such as transportation/location, financial barriers, access to services, stigma or discrimination, and physical issues.

A common struggle for caregivers who are trying to get their loved ones reengaged with the community is a broad lack of support outside the family and few resources available to those in need.

Peer support and other forms of community engagement can close the gap between people with mental illness and their surroundings. The feeling that they have purpose and belong to

something bigger than themselves can play a critical role in the recovery of loved ones.

A 2016 survey by Mental Health America (MHA) surveyed caregivers on the eight domains of community inclusion. Here are some of the results:³

> **Housing:** Forty-five percent of people with mental illnesses receiving care in the home of their caregiver, yet only one-third of caregivers reported that their loved one was involved or very involved with their choice of housing. It may be hard for your loved one to find and keep a home, but there is hope no matter where they are. Supervised and partially-supervised group housing, supportive housing, and rental housing may be good options. Try looking in your community for housing-first initiatives, community development agencies, and home ownership programs

> **Employment:** A majority of caregivers reported that their loved one had very little involvement with competitive employment, with just 18 percent reporting their loved one was actively involved. In the past, people with mental illness were often discouraged from working; today, we understand that work is not only a possibility, but also can play a vital role in recovery. Training programs, supported employment or individual placement programs, mentors, and employment specialists can help your loved one find employment.

- > **Education:** Less than 25 percent of caregivers responding to the survey reported that their family member was involved or very involved with school supports. Education can accelerate your loved one's recovery through broadening their intellectual, social, and emotion horizons. Community and career colleges, supported education, special education and alternative secondary schools, GED and high school equivalency programs and academic accommodations can offer academic opportunities for your loved one.
- > **Health and wellness:** Thirty percent of caregivers reported that their loved one was involved or very involved in health and wellness activities. What is good for your body is good for your mind. Community health clinics or gyms offer a variety of programs. If your loved one is dealing with an issue like Bipolar Disorder, consider support groups through an organization like Depression and Bipolar Support Alliance (DBSA). Find your local MHA affiliate and see what programs they offer at <https://arc.mhanational.org/find-affiliate>.
- > **Religion:** Some caregivers found that their loved one's religious organization was often the only inclusive community institution. Not only can religious involvement help your loved one find connections, but it may also directly benefit their mental health.⁴ If your loved one is interested, you can

encourage participation in congregation, bible study groups, trips, food drives or volunteer work.

- > **Friendships:** Caregivers reported that their loved ones had extremely low involvement (26 percent) with friends. Think about your loved one's interests and what they like to do for fun, and together you can search for interest-based groups through apps like Meetup or Facebook or online community support tools like MHA's Inspire Community <https://www.inspire.com/groups/mental-health-america>. These platforms offer opportunities for your loved one to meet people who participate in activities that may interest them. Another option is connecting with a community mentor from a local agency.
- > **Family and intimate relationships:** Fifty-four percent of caregivers reported their loved one was involved or very involved with family. It's important to remember that when it comes to family –relationships can take time to heal. Re-establishing normalized roles within existing family settings (child, parents, sibling, uncle/aunt) are common long-term goals. Caregivers reported that just twenty-five percent of their loved ones were involved in intimate relationships. Intimate relationships may be most appropriate when your loved one has reached a certain point in their recovery.

PEER SUPPORT

Peer support offers individuals living with a mental illness the opportunity to connect with someone like them, who understands them. Rooted heavily in themes of trust and compatibility, peer support specialists are trained to teach skills, and help individuals in recovery lead a meaningful life in their community. Peers can help educate, mentor, and motivate your loved one by relating their own unique experience living with mental health conditions to that of your loved one.

Peer support has been found to be related to the following health outcomes and benefits:⁵

- The sense of togetherness can model recovery and offers hope
- Increased sense of control and ability to bring about change in his/her own life
- Increased sense that treatment is responsive and inclusive of needs
- Increased engagement in self-care and wellness
- Decreased psychotic symptoms
- Reduced hospital admission rates
- Decreased substance use and depression

Peer support can help your loved one learn skills, give them the support they need, and promote inclusion in their community to achieve a full and satisfying life.

It can be hard for caregivers to connect with their loved ones if they don't have the same first-hand experiences as them. It is important to remember that just because you may not be able to relate with your loved one like you wish or feel you should, it does not make you any less valuable for that person, nor does it undermine your relationship with them.

Contact your local MHA affiliate to get information about peer support groups, drop-in centers or peer respite in your area at <https://arc.mhanational.org/find-affiliate>.

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BE PREPARED: CRISIS PLAN WORKSHEET



If you or your loved one is experiencing a mental health crisis, it can be hard to make sure proper care is given. Psychiatric advance directives (PADs) are legal documents completed in a time of wellness that make it possible for people with mental illness to determine what type of care they would like to receive in a crisis, should they not be able to make decisions. PADs can be a lifesaving tool, help caregivers ensure their loved one's voice is heard, and facilitate dialogue with providers.

This worksheet outlines what you will need in order to complete a PAD, but is NOT an official PAD. In order to complete a PAD, you must check with your state about legal forms and requirements. Without legal documentation, this worksheet does not count as a PAD – but it does cover the majority of questions you or your loved one will want to consider.

After you or your loved one completes this worksheet, take the steps to complete a formal PAD - or just use this worksheet as a reference in the event of a crisis. *Please note: The questions below are meant to be directed to and answered by the person with a mental illness, not the caregiver.*

> **SIGNS OF CRISIS.** Think about the last time you knew you were in crisis, what were some of the signs or symptoms that something was wrong, or that things were getting worse? (ex: not sleeping for 4 days, drinking more than usual) Be as specific as possible.

> **TRIGGERS FOR CRISIS.** What kinds of triggers or situations may cause you to experience a mental health crisis? Think about the last time you were in crisis, what events led up to it?

> **HOSPITALIZATION PREVENTION.** What can help you prevent a mental health crisis? Consider what you or others can do to help keep you from an unwanted hospitalization. (ex: social support from those who may be watching out for me)

> **EMERGENCY CONTACTS.** Who do you want to be contacted during an emergency? List any family, friends or people on your care team like your therapist or case manager.

Name: _____ Relationship to me: _____

Address: _____ Phone number: _____

Name: _____ Relationship to me: _____

Address: _____ Phone number: _____

Name: _____ Relationship to me: _____

Address: _____ Phone number: _____

> **LESSONS FROM PAST EXPERIENCES.** If you have been in the hospital before, share specific ways you reacted. Were there any aspects that made you uncomfortable? (ex: I do not want to be alone when I see X provider. I do not want student observers in the room.)

> **VISITATION PERMISSION.** If you are in the hospital, who can come visit you? Remember to add them to authorization lists during intake.

> **FACILITY PREFERENCES.** Should you need to attend a hospital, do you have a preference regarding which hospital you go to? Briefly explain why or why not.

a. I would prefer to attend the following hospital(s) in the future: _____

b. I would *not* like to attend the following hospital(s) in the future: _____

c. Other information/requests regarding hospitalization: _____

> **PREFERENCES FOR STAFF INTERACTIONS.** Are there specific things staff can do that would make you feel more comfortable or relaxed? (ex: I would like to be warned before staff touch me.) Provide any information about yourself that may be helpful in aiding staff treating you in the event of a crisis.

> **MEDICATION PREFERENCES.** Are there any psychiatric medications you would prefer or prefer not to be given in a crisis? Briefly explain why or why not (ex: bad side effects).

a. I would like to be given the following medication(s): _____

b. I would *not* like to be given the following medication(s): _____

c. Other information (allergies, side effects): _____

> **TREATMENTS I DO NOT CONSENT TO.** Are there any treatments you do not wish to receive? (ex: electro-convulsive therapy (ECT))

> **OTHER INSTRUCTIONS.** What other things may need to be taken care of if you are in the hospital? Do you need assistance taking care of pets, paying bills, watering plants, etc.? List any other instructions you may have, and any other medical conditions doctors should be aware of. If you create a PAD, you may list specific instructions regarding the sharing of your advanced directive here.

> **LEGAL DOCUMENTATION.** In order to create a psychiatric advance directive, you must check with your state and fill out the appropriate forms. If your state does not have one, its statute should list criteria for creating your own valid form. Most states require your PAD form to be formally signed by a witness, or potentially notarized. Witnesses generally may not be family or one of your providers. Once complete, give your psychiatric advance directive to your physician and other mental health treatment providers so they may add it to your medical record. Check your state's specific requirements and forms to complete your PAD here at www.nrc-pad.org.