

Mental Health Support in Blistering Disease: Why, When, What, and How to Find It

Marney White, PhD, MS

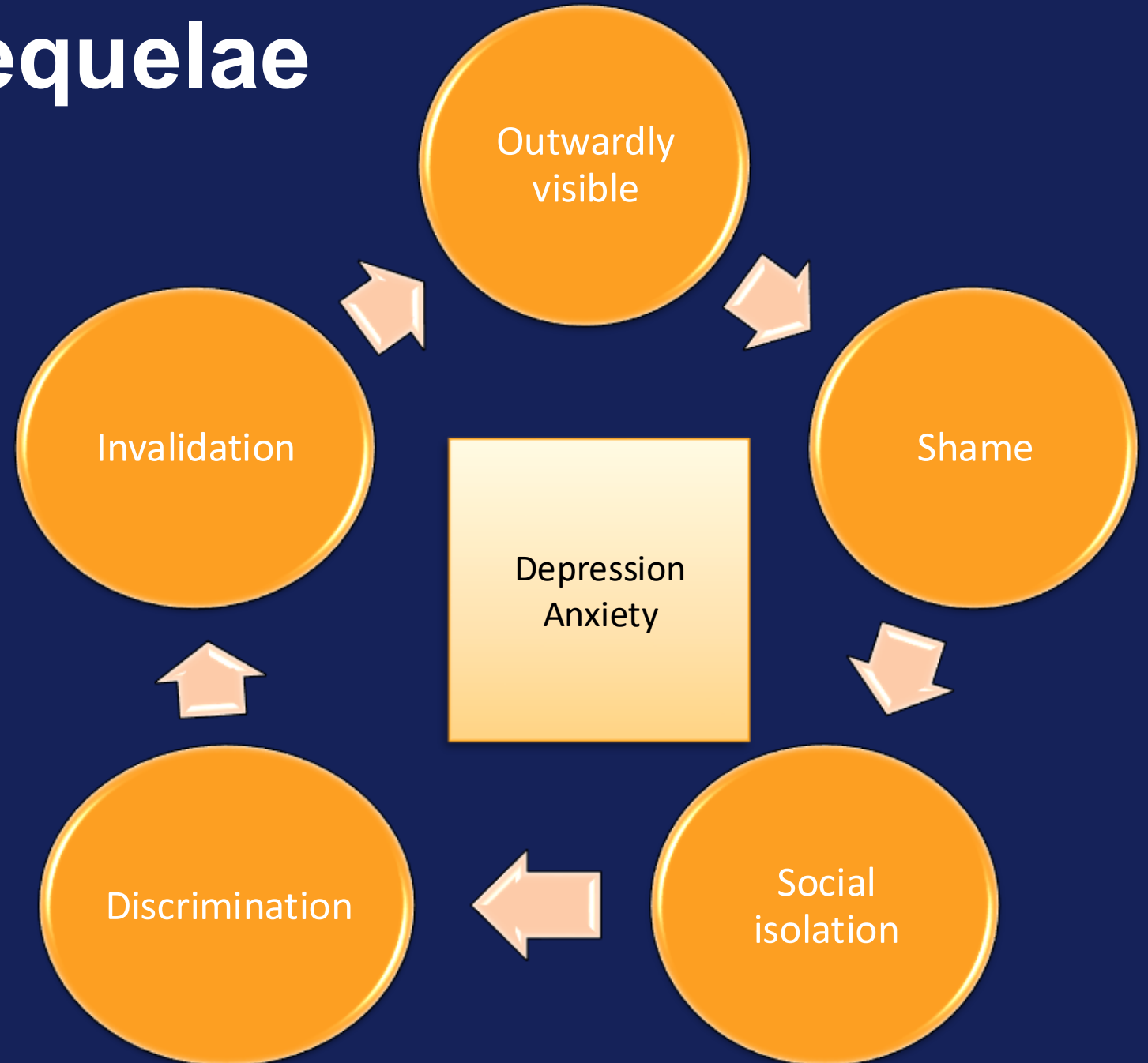
Yale School of Public Health

Yale School of Medicine

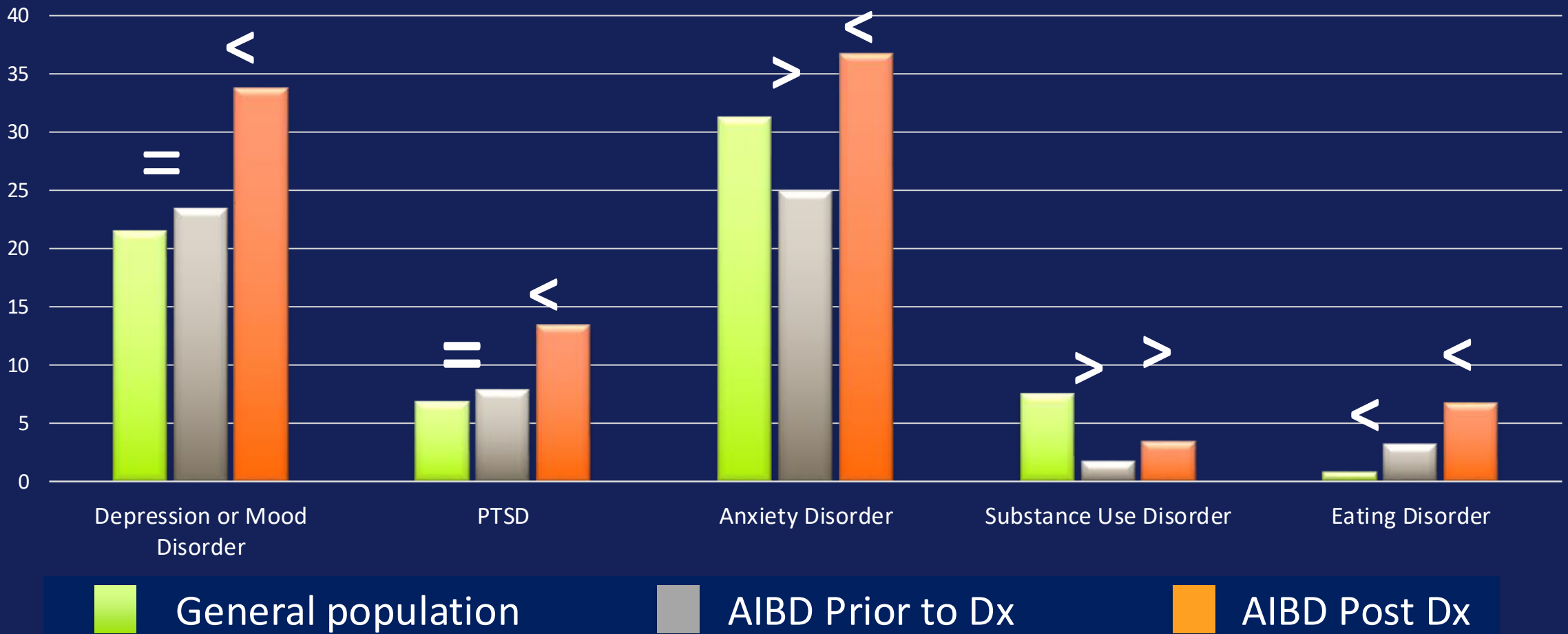


Psychological Sequelae

- **Treatments:** cause significant weight gain, “moon face,” lead to fatigue, severely immunocompromising
- **Chronicity:** cycle of blister, treatment, healing, recurrence
 - Taxing on resilience



Q: How common are anxiety or depression in people living with pemphigus or pemphigoid?



Q: How can patients tell the difference between normal frustration and clinical depression or anxiety?

Q: What are the warning signs that stress or sadness has turned into something that needs professional help?

Q!: What are some of the more common emotional responses to a chronic diagnosis that people experience that may serve as warning flags?

Q: Is it normal to feel grief or loss after being diagnosed with a chronic autoimmune disease?

Depression symptoms (ABCs)

- Affect: persistent sad, anxious or “empty” mood, low energy, hopelessness
- Behavior: appetite, sleep, drugs/alcohol, social withdrawal, libido, psychomotor
- Cognition: difficulty concentrating/decision making, guilt, thoughts of death or dying

Anxiety symptoms

- Cognition – persistent worry, difficulty concentrating, catastrophizing
- Physical – restlessness, easily fatigued, difficulty concentrating, irritable, muscle tension, sleep disturbance
- Behavioral avoidance, checking, worry that feels difficult to control



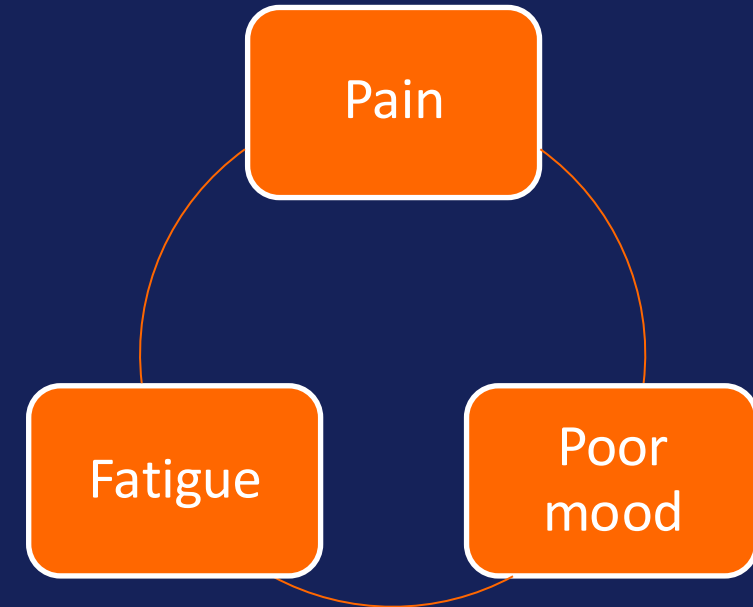
Clinical significance

- Sad mood, anxiety, and physical features of depression and anxiety are NORMAL experiences
- Determining “clinical significance” for diagnosis:
 - The mood and/or anxiety symptoms interfere with social and/or occupational functioning
- Clinical significance in chronic disease may be a different threshold

Why Mental Health Support Matters

Q: How can patients manage the emotional impact of pain, eating difficulties, or fatigue?

- Severe chronic disease affects emotional and psychological wellbeing
- Common challenges include grief, uncertainty, identity disruption, and anxiety
- Psychological support can improve coping and quality of life



Psychological treatment **improves disease course** in other severe chronic disease!

Stress Reduction Interventions in Chronic Disease

- Clinical trials have demonstrated:
 - improved psychological function, quality of life



(Claar & Blumenthal, 2003)

Psychological Intervention Improves Survival

- 227 patients surgically treated for breast cancer
- Randomized to
 - Assessment + **Intervention**
 - Assessment Only
- **Intervention**: stress reduction; mood improvement; boost health behaviors; increase adherence



Andersen et al. (2008)

Results



Intervention patients:

- Reduced risk of breast cancer recurrence
- Reduced risk of death due to breast cancer
- Reduced risk of death from all causes



Therapy in Chronic Illness

- Coping with ongoing medical symptoms
- Adjusting to changes in identity, roles, and independence
- Managing uncertainty about health and the future
- Navigating relationships with caregivers and family
- Tailored to individual needs
 - *Body image, pain management, depressed mood, fatigue, and more...*

The goal is often improved quality of life and resilience rather than 'fixing' the illness.

Types of Mental Health Providers

Psychotherapy

- Clinical psychologists (PhD or PsyD)
- Counseling psychologists (PhD)
- Licensed clinical social workers (LCSW)
- Licensed professional counselors (LPC)
- Marriage and family therapists (LMFT)
- Licensed mental health counselors (LMHC)

Medication management

- Psychiatrists (MD)
- Psychiatric nurse practitioner (APRN)
- Physician's Assistant (PA)
- Clinical Psychologists (*in some states*)



Important! Look for a *licensed* provider

Where to Find Therapists

Insurance company provider list

Physician recommendation

Major directories:

- Psychology Today therapist directory
- American Psychological Association Psychologist Locator
- Search engines

These allow filtering by specialty, location, insurance, modality, and therapy approach

Using the Psychology Today Directory

- Search by zip code or city
- Filter by issues (depression, anxiety, chronic pain)
- Filter by insurance accepted
- Review therapist profiles describing their approach and experience
- Can search by telehealth and in-person

Psychology Today (website)

The screenshot shows the Psychology Today website interface. The browser address bar displays `psychologytoday.com/us/therapists/06824`. The page title is "Therapists in 06824". A search bar at the top contains "Therapists" and "City, Zip or Name". Below the search bar, there are filters for "Female" and "Male". The main content area displays two therapist profiles: Lisa A Fournier and Nicole Salati. A "Filters" overlay is open on the right side of the page, listing various mental health conditions and issues. The "Filters" overlay includes a "Clear All Filters" button and a "Show 13 Therapists" button.

Psychology Today Therapists City, Zip or Name

Home > Connecticut > 06824

Therapists in 06824

Female Male

Lisa A Fournier
Marriage & Family Therapist, LMFT, LA
Fairfield, CT 06824

I see the therapeutic relationship as the key to the creation of a safe, emotionally-open environment where clients can access their own untapped resources. I am a Licensed Family Therapy, Certified and Licensed Professional Counselor.

Nicole Salati
Licensed Professional Counselor, MS, LPC
Fairfield, CT 06824

I'm a Licensed Professional Counselor with a Master's in Counseling Psychology from Pace University, and I have worked with individuals, couples, and families find clarity, connection, and healing. I am collaborative, compassionate, and trauma-informed.

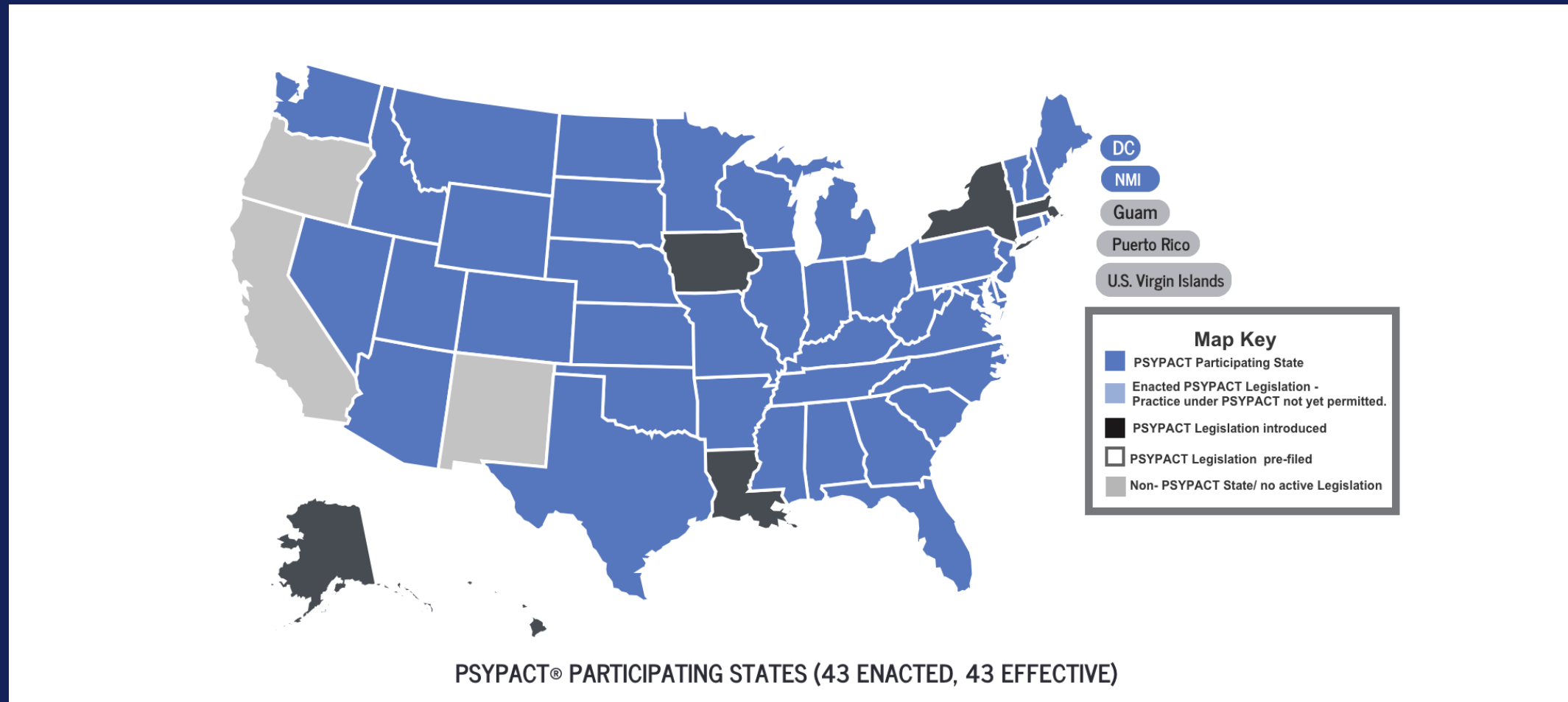
Filters

- Behavioral Issues
- Bipolar Disorder
- Body Image
- Borderline Personality (BPD)
- Cancer
- Career Counseling
- Child
- Chronic Illness
- Chronic Pain
- Codependency
- Dementia
- Depression
- Dissociative Disorders (DID)
- Divorce
- Domestic Abuse
- Drug Abuse
- Infertility
- Infidelity
- Intellectual Disability
- Internet Addiction
- Life Coaching
- Marriage Counseling
- Medical Detox
- Medication Management
- Men's Issues
- Narcissistic Personality (NPD)
- Obesity
- Obsessive-Compulsive (OCD)
- Open Relationships Non-Monogamy
- Oppositional Defiance (ODD)
- Parenting
- Sex-Positive, Kink Allied
- Sexual Abuse
- Sexual Addiction
- Sleep or Insomnia
- Spirituality
- Sports Performance
- Stress
- Substance Use
- Suicidal Ideation
- Testing and Evaluation
- Transgender
- Trauma and PTSD
- Traumatic Brain Injury (TBI)
- Veterans
- Video Game Addiction
- Weight Loss

Clear All Filters

Show 13 Therapists

PsyPact (virtual only – 43 states)



PsyPact (virtual only)

The screenshot shows the PsyPact Directory website. The browser address bar displays "directory.psympact.gov/?1308=cancer&page=1". The website header includes the PsyPact logo, navigation links (ABOUT, COMMISSION, PSYPACTMAP, AUTHORIZATION TO PRACTICE, VERIFY, LEGISLATIVE RESOURCES, SIGN IN), and social media icons. Below the header, it says "PSYPACT Directory" and "16,401 Directory Members". A blue banner with a megaphone icon reads "Need help navigating the directory? Check out our tutorial on YouTube!". The search area includes a search bar with "Search by...", a dropdown for "Profile Name", and a filter dropdown set to "Default (Most completed)". Below the search bar, it says "Viewing 1-14 of 14" and "Page 1 of 1". A member profile for Kelly McClure, PhD, ABPP, is shown, including a photo, location (Philadelphia, PA, USA), and a bio: "I am a Board Certified Clinical Psychologist in private practice. I specialize in cognitive behavioral therapy to help adults and older teens who are struggling with depression, anxiety, ADHD, or health issues and are looking for a compassionate and experienced therapist to listen to their stories and support them. Through our work together, I help people understand their struggles in a new way and find a different path forward." A blue badge below the profile reads "Authority to Practice Interjurisdictional Telepsychology - Annual Renewal".

Areas of Specialty

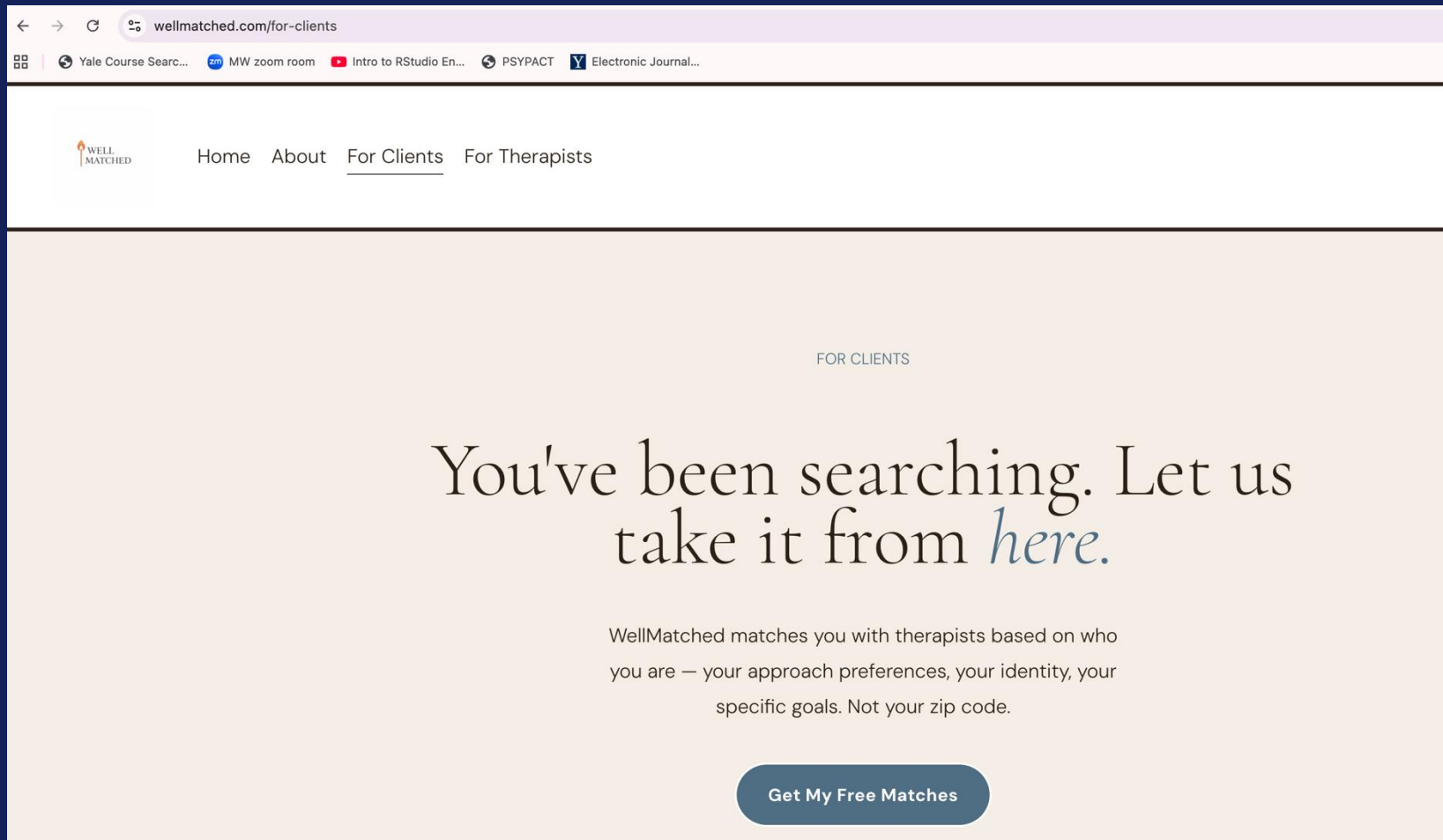
- Abuse Survivors
- ADHD/Learning Disorders
- Aging
- Addictive Behaviors
- Alzheimers/Dementia
- Anger Management

Areas of Specialty- Other

Ages Served

- Infants/Young Children: 0-5
- Children: 6-12
- Adolescents: 13-18
- Young Adults: 19-27
- Adults: 28-64
- Older Adults: 65+

Virtual/ telehealth option: Wellmatched



The screenshot shows a web browser window with the URL `wellmatched.com/for-clients`. The browser's address bar and tabs are visible at the top. The website's navigation menu includes [Home](#), [About](#), [For Clients](#) (which is underlined), and [For Therapists](#). The main content area has a light beige background and features the text "FOR CLIENTS" centered at the top. Below this, a large heading reads "You've been searching. Let us take it from *here.*". Underneath the heading, a paragraph states: "WellMatched matches you with therapists based on who you are — your approach preferences, your identity, your specific goals. Not your zip code." At the bottom center, there is a dark teal button with the text "Get My Free Matches".

wellmatched.com/for-clients

Yale Course Searc... MW zoom room Intro to RStudio En... PSYPACT Electronic Journal...

WELL MATCHED Home About For Clients For Therapists

FOR CLIENTS

You've been searching. Let us take it from *here.*

WellMatched matches you with therapists based on who you are — your approach preferences, your identity, your specific goals. Not your zip code.

Get My Free Matches

Relevant Specialties to Look For

- Chronic illness
- Health psychology
- Pain management
- Medical trauma
- Disability and adjustment
- Behavioral medicine

- Cancer

Using the APA Psychologist Locator

Locator.apa.org

- Directory of licensed psychologists
- Search by location or specialty
- Useful for finding doctoral-level clinicians
- May include providers with expertise in complex medical or psychological issues

The screenshot displays the APA Psychologist Locator website interface. The browser address bar shows the URL: locator.apa.org/results/1/Fairfield,%20CT/50/Cancer/. The page header includes the logo for the Psychologist Locator, an official product of the American Psychological Association, and a navigation bar with options like 'Home' and 'Search Results'. A search bar on the left allows refining results by location (Fairfield, CT), distance (50 miles), and specialty (Cancer). A 'SEARCH' button is visible. The main content area shows search results for 'Chanchal Sharma' in New York, 'Karen Seelert' in Connecticut, and 'Clare Campbell' in Connecticut. Each result includes a profile picture, name, address, insurance accepted, and a button to 'Email Psychologist'. A yellow banner indicates that the results are within the selected distance but may not be an exact match. A section titled 'Need More Help? Contact Your State Psychological Association' provides a dropdown menu to select a state or territory and a 'Go' button.

Positive Signs in a Therapist Profile

Good indicators include:

- Experience working with medical populations
- Clear explanation of treatment approach
- Collaboration with medical providers
- Clear treatment goals
- Transparent policies and expectations

Possible Red Flags

Be cautious if:

- Credentials or license are unclear
- No information about training or specialization
- Promises of quick or guaranteed results
- Very broad or vague claims of expertise
- Insurance bait-and-switch

Questions to Ask a Potential Therapist

- Have you worked with people with chronic illness?
- What therapy approaches do you use?
- How do you evaluate therapy progress?
- Do you coordinate care with medical providers?
- What does a typical course of therapy look like?

Therapies that Work (empirically supported psychotherapies)

Filter Results

Psychological Treatments Archive 84 —

- Alcohol Use 3
- Anxiety 8
- Attention Problems 2
- Depression 23
- Eating 8
- Eating Problems 1
- Nicotine/Tobacco Use 1
- Obsessions/Compulsions 2
- Other Health Conditions 1
- Pain 5
- Personality 4
- Psychosis 9
- Relational 2
- Sleep 5
- Substance Use 5
- Traumatic Stress 8
- Weight Management 2

Cognitive Behavioral Therapy for Chronic Headache

Status: Strong Research Support
What does this mean? Description When a stressor is perceived, the...

Behavioral and Cognitive Behavioral Therapy for Chronic Low Back Pain

Status: Strong Research Support
Behavioral Therapy (BT) and Cognitive Behavioral Therapy (CBT) for CLBP are terms for psychological interventions...

Acceptance and Commitment Therapy for Obsessive-Compulsive Disorder

Status: Modest Research Support
Description Acceptance and Commitment Therapy (ACT) is a behavioral therapy that is based on Relational Frame...

Multi-Component Cognitive Behavioral Therapy for Rheumatologic Pain

Status: Strong Research Support
Cognitive Behavioral Therapy (CBT) for Rheumatologic pain conditions is based upon the idea that adaptation to...

Society of Clinical Psychology (APA)

<https://societyofclinicalpsychology.org/>

Evidence-Based Therapy Approaches

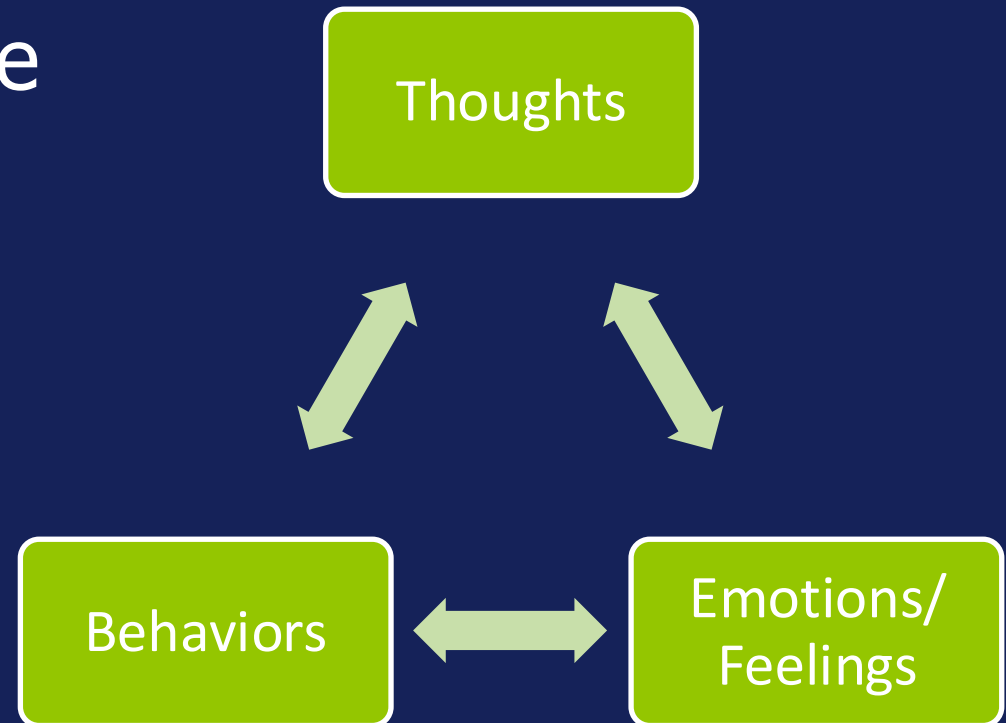
Therapies commonly used for chronic illness include:

- Cognitive Behavioral Therapy (CBT)
- Acceptance and Commitment Therapy (ACT)
- Mindfulness-based therapies (stress management)
- Trauma-informed therapy

Experience applying these approaches to medical illness is important.

Cognitive Behavioral Therapy

Identify patterns of negative thinking and learn to change or restructure them



Acceptance and Commitment Therapy (ACT)

- Pain and discomfort are a normal part of the human experience.
- Psychological suffering increases when we try to avoid or control internal experiences.
- People can live more fulfilling lives by increasing psychological flexibility—being present, open, and committed to valued actions.

The First Therapy Session

In the first session, therapists typically:

- Ask about your medical history and current health challenges
- Discuss emotional and psychological concerns
- Ask about relationships, support systems, and daily life
- Talk about goals for therapy
- Explain how sessions typically work
- The first meeting is often about getting to know each other and determining whether the therapist feels like a good fit

Key Takeaway

Credentials matter—but fit matters too.

A strong therapist match should include:

- Proper licensure
- Relevant experience
- Evidence-based approaches
- A collaborative relationship where the patient feels understood

Q: How do you cope mentally with the fear of disease coming back or if someone has a flare, how to not catastrophize or become panic and jump to some of the worst case scenarios?

- Multiple studies reporting positive effects of Cognitive Behavioral Therapy and Acceptance and Commitment Therapy for reducing recurrence fears in cancer
- We have learned that in AIBD, fears of recurrence are even higher
- Suggests that these interventions are critically needed because fears of recurrence also affect overall mental health

Table 2. Resources to Help Patients Cope With Fear of Cancer Recurrence (FCR)

FCR-Specific Websites

Australia

Cancer Council NSW: *Fear of the Cancer Coming Back*

<https://www.cancer council.com.au/15291/cancer-information/after-treatment/when-treatment-finishes-after-treatment/living-well-after-cancer-fear-of-recurrence/>

Breast Cancer Network Australia: *Fear of Breast Cancer Recurrence and Fear of Breast Cancer Progression Resources Available*

<https://www.bcna.org.au/news/2017/07/fear-of-breast-cancer-recurrence-and-fear-of-breast-cancer-progression-resources-available/>

United States

Cancer.net: *Coping With Fear of Recurrence*

<http://www.cancer.net/survivorship/life-after-cancer/coping-with-fear-recurrence>

Memorial Sloan Kettering Cancer Center: *Six Tips for Managing Fear of Cancer Recurrence*, by Esther Napolitano

<https://www.mskcc.org/blog/six-tips-managing-fear-recurrence>

United Kingdom

Macmillan Cancer Support: *Worrying About Cancer Coming Back*

<http://be.macmillan.org.uk/Downloads/CancerInformation/Living-WithAndAfterCancer/MAC14215WorryingE02lowrespdf20170713SCM.pdf>

Therapy and Support Groups for Cancer Survivors

Flinders University, South Australia: *Finding My Way*

Finding My Way is an online intervention providing access to information and strategies to improve cancer patients' physical and mental well-being during and after treatment.

<https://findingmyway.org.au>

American Cancer Society: *Cancer Survivors Network*

<https://csn.cancer.org>

Relationships

- How can patients maintain relationships when they are dealing with fatigue, pain, or visible symptoms?
- Are there any suggestions on ways to discuss this with friends/family? What about co-workers and my boss?



Reasonable Accommodations for Autoimmune Diseases

Katherine R.

We all know how extremely difficult it is to manage a rare autoimmune disease. Besides experiencing painful and difficult symptoms, we must deal with doctors' offices, insurance companies, pharmacies, and the side effects of drugs. Sometimes, having pemphigus or pemphigoid (P/P) feels like a full-time job.

But what happens when you are actually working full time? The stress of balancing work and illness can be completely overwhelming. For those working P/P patients, it is important to understand what rights exist and what resources are available, especially for those who need to continue to work full time while they are ill.

In the United States, having an autoimmune disease can be considered a disability.¹ Under the American with Disabilities Act (ADA), any medical issue that severely

impacts a person's quality of life or life function is considered a disability, and a person with a disability is entitled to a reasonable accommodation to help assist them in their job.

What is an accommodation?

A reasonable accommodation is any change or adjustment to a job or to the work environment that allows a person with a disability to perform the essential functions of their job. In other words, a reasonable accommodation is when the employer changes the way things are customarily done that allows an individual with a disability to enjoy equal employment opportunities.

¹While this article focuses on policy within the United States, there are similar disability laws in the UK, Canada, and around the world. <https://www.un.org/development/desa/disabilities/disability-laws-and-acts-by-country-area.html>

Am I Sick Enough for an Accommodation?

An individual can qualify for a reasonable accommodation if they have "a physical or mental impairment that substantially limits one or more major life activity." So, if you have symptoms of your illness that interfere with a major life activity, such as work, sitting, standing, talking, etc., you may qualify for an accommodation.

A person does not have to "look sick" to be sick. A person may suffer from symptoms like fatigue, brain fog, joint pain, blistering, swelling, unexplained weight changes, inability to concentrate, rapid heart rate, abdominal pain, poor coordination, and other symptoms that are not visible to their employer. Your illness does not need to be visible to be accommodated.

Am I Qualified to Request an Accommodation?

First, an employee with a disability must be able to perform the essential functions of their job with or without an accommodation. Essential functions are job duties that are fundamental to the position. For example, a teacher must be able to work with children, a bus driver must be able to drive, and a butcher must be able to use a knife.

Second, under the ADA, not all employers are legally required to provide accommodations, although smart ones do! Employers who have 15 or more employees are generally legally required to provide reasonable accommodations. Some state and local laws may require that employers with fewer employees provide reasonable accommodations. If you work for a smaller company, check your state or city laws to see what applies in your area.

Nervous about Requesting an Accommodation?

In many cases, requesting an accommodation, for any reason, and especially for an autoimmune disease, can be a difficult process to start. If you are not comfortable with sharing personal information, the process of requesting an accommodation may seem daunting or scary. However, there are two significant benefits to sharing. First and foremost, you may get the accommodation you need to make your job easier and your life better. Second, the pure act of disclosing your health information and requesting an accommodation provides some legal protection, as your employer cannot legally

retaliate against you for making such a request or having a disability.

Preparing to Request an Accommodation

There are several ways that you can prepare for requesting an accommodation which will make the whole process easier to manage.

Consider what limitations you are currently experiencing. Do you have difficulty sitting? Getting dressed? Are you in pain? Do you have limited mobility? Do you need time to take care of your blisters? Make a list of these limitations.

Ensure you have the necessary medical documentation from your medical provider. Certain medical providers may be uncomfortable with providing such letters because of the Health Insurance Portability and Accountability Act (HIPAA). However, with your authorization, medical providers can release limited information.

Ensure that your medical documentation is sufficient. Make sure your medical documentation is on office letterhead, dated, and signed by your medical provider. You can always supplement any documentation with test results. Make sure that your diagnosis/diagnoses and your limitations are also clear. You may ask your medical provider to include your diagnosis, your current medication, and your limitations. For example, your note could say, "Ms. Smith has pemphigus vulgaris and is being treated with Rituxan®. Ms. Smith is experiencing fatigue, aches, and is managing blistering and open wounds. Ms. Smith also needs to attend weekly physical therapy."

Don't overshare. If you have pemphigus, but also have asthma, irritable bowel syndrome (IBS), and diabetes,

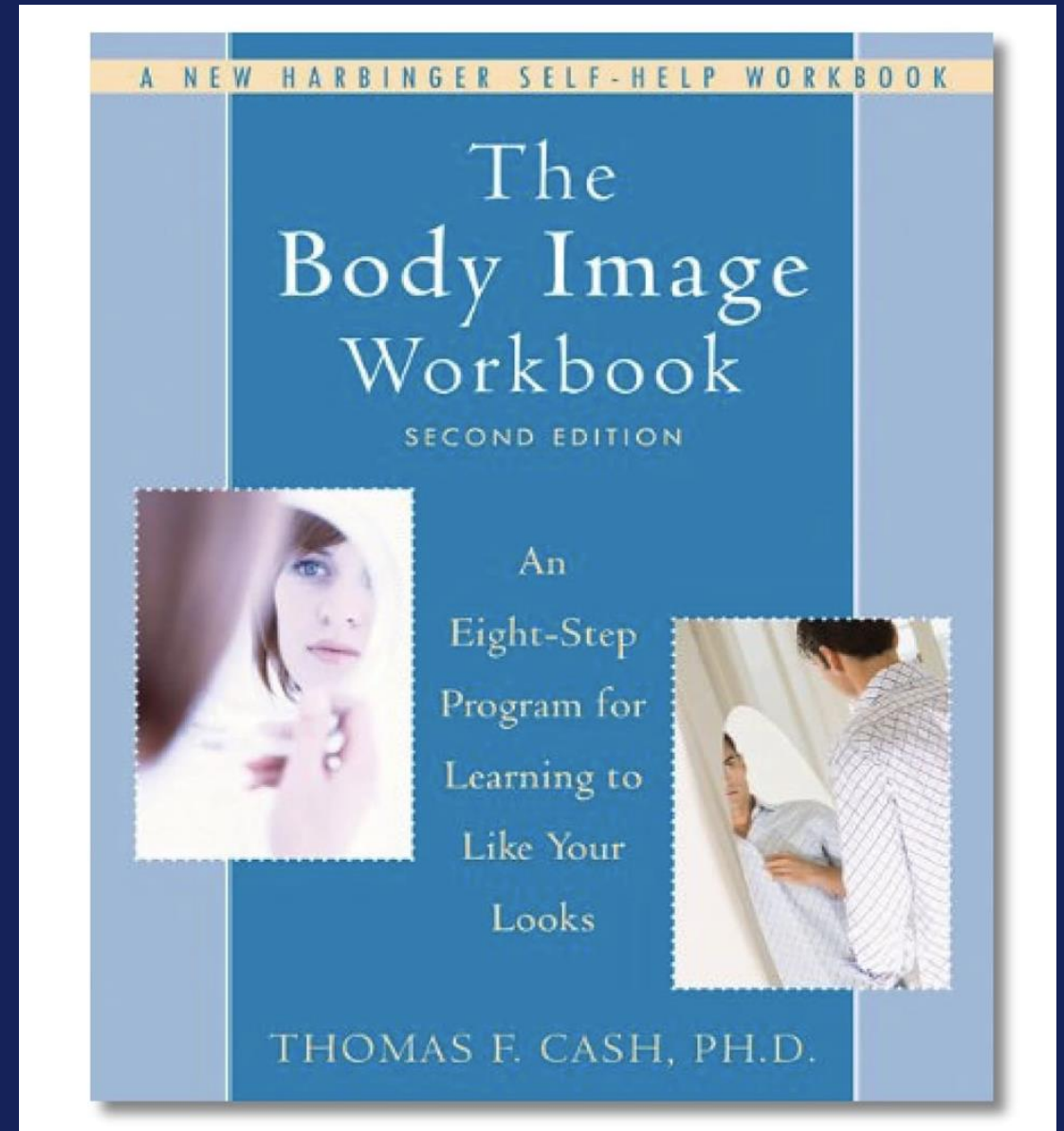
An individual can qualify for a reasonable accommodation if they have "a physical or mental impairment that substantially limits one or more major life activity."

CONTINUED

Body Image

What strategies help with body image issues caused by skin lesions or scarring?

I am so embarrassed and scared about my recent diagnosis and lesions all over my body.



What mental health challenges do caregivers of pemphigus or pemphigoid patients experience?

How can caregivers support patients without experiencing burnout themselves?

- Limited research focused on caregivers and families in AIBD
 - Documented impairment, reduced quality of life
 - Recommended counseling (no tested programs)
- Recommend drawing from existing research in severe chronic disease
 - Caregivers also benefit from group/ social support and counseling

Caregiver support



CT.GOV | State of Connecticut

Aging and Disability Services

Home About Us Programs And Services Additional Resources FAQ Contact Us

SHARE

What is the National Family Caregiver Support Program?

Date: August 04, 2025
Read time: 2 minutes

The National Family Caregiver Support Program offers caregivers a much-needed break to rest and recharge, both physically and emotionally. The program provides funding for a range of services that support family members and other unpaid caregivers. This includes those caring for older adults, grandparents and older relatives raising grandchildren, and parents caring for an adult child with a disability.



Helping Caregivers of Loved Ones with Pemphigus and Pemphigoid Avoid Caregiver Burnout

Marvell Adams, Jr.

What is caregiver burnout?

The fact that caregiving can be stressful is nothing new. You may feel that no matter what you do, it's not enough, or everything is on your shoulders. You may feel overwhelmed, anxious, or frustrated. If you don't address it, this stress can lead to caregiver burnout over time.

Many aspects of caregiving for a loved one can lead to burnout. You may feel other family members aren't helping as much as they should be. There's just too much to do and not enough time to do it. Once your loved one finally gets a diagnosis, there are all the doctor appointments—often requiring travel to a major teaching hospital to see a specialist—and the time it takes to help your loved one with things like dressing changes. With all the demands on your time, you may not have any time for yourself.

The pain and discomfort that comes with pemphigus and pemphigoid may cause your loved one to be depressed, disagreeable, and withdrawn from the outside

world. This isolation can carry over to the caregiver, leading to depression and other symptoms of burnout.

As a caregiver, you may have unreal expectations. In a perfect world, with you as a caregiver, your loved one would get treatment and recover completely. Sadly, life doesn't always work that way. You may feel afraid and have feelings of uncertainty about the future. You may feel guilty, thinking you should be doing more, or neglecting other family members.

Caregiver burnout can affect your mood and make you tense, angry, anxious, depressed, irritable, frustrated, or fearful. It can make you feel out of control, helpless, unable to focus, or lonely. Caregiver burnout can also cause physical symptoms such as trouble sleeping, muscle tension (back, shoulder, or neck pain), headaches, stomach problems, weight gain or loss, fatigue, chest pain, heart problems, hair loss, skin problems, or colds and infections.

Q: Why don't more dermatologists ask about our mental health when we are diagnosed or in treatment with pemphigus and pemphigoid?

- We are trying!
- Advocating for psychological screening and referral as standard of care

Q: Why do you think there is such a stigma around getting support for our mental health? Do you feel that this is changing in recent society?

- Lack of awareness
- Lack of standards of care



The IPPF Natural History Registry uses an online data system to collect anonymous data that:

- Reflects the true burden of your condition
- Shows treatment efficacy
- Measures your quality of life
- Can inform decision-makers about your experience

6 New Surveys Added!

The IPPF hopes that these new surveys will help us answer many more unanswered questions about pemphigus and pemphigoid through your help!

PRIDD

ABQOL

TABQOL

COMDQ-15

Diet Survey

Patient's Experience with Pemphigus and Pemphigoid

Thank you!

Questions?