Help for the Ombudsman

Assisting the Adult Home Resident

Susan Wehry, M.D.

Associate Professor of Psychiatry Consultant, Mental Health and Aging Initiative

2002 LTCOP Annual Training Conference
October 9-11, 2002 Saratoga Springs, N.Y

Topics

- Who's Who in Adult Homes
- Communication skills
- Medications
- Recovery and Illness Self-management
- The Ombuds Toolkit

{||||

Who's Who

- People
- People with stories
 - Successes
 - Trauma
 - Incarceration
 - Losses
- People with mental illness
- People who are marginalized
- People who are stigmatized



Why does stigma still exist?

Media

- Newspapers, stress history of mental illness in crimes of violence
- Television sensationalizes crimes
- Comedians use disabilities as
- National advertisers use stigmatizing images as promotional gimmicks

Your role

- **To see individuals**
- To talk with individuals
- To hear individuals
- **■** To support recovery
- **■** To talk about individuals

What you are up against

- Stigma
- Media spotlight
- Demoralized residents
- Demoralized minimum-wage aides
- Angry communities

- What is mental illness
 - -Diseases that
 - »cause mild to severe disturbances in thought, feeling and/or behavior

»result in an inability to cope with life's ordinary demands and routines

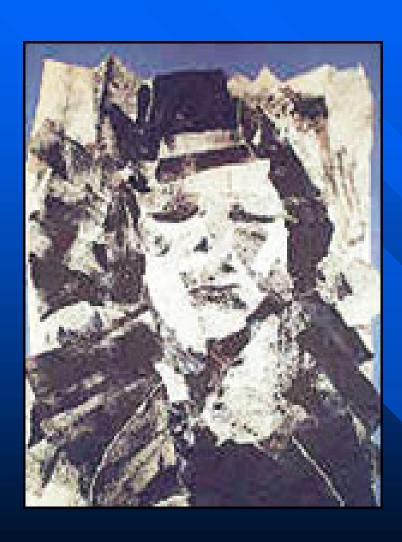
- > 200 classified forms of mental illness
 - common disorders
 - » depression, bipolar disorder, dementia, schizophrenia, substance abuse, anxiety
 - related to
 - » excessive stress due to a particular situation or series of events
 - » caused by a reaction to environmental stresses, genetic factors, biochemical imbalances, or a combination of these

- Myth: 'People who need psychiatric care should be locked away in institutions."
 - Fact: Today, most people can lead productive lives within their communities with a variety of supports, programs, and/or medications
- Myth: "A person who has had a mental illness can never be normal."
 - Fact: People with mental illnesses can recover and resume normal activities

- Myth: "Mentally ill persons are dangerous."
 - Fact: The vast majority of people with mental illnesses *are not* violent. When violence *does* occur, it typically results from the same reasons as with the general public such as feeling threatened or excessive use of alcohol and/or drugs
- Myth: "People with mental illnesses can work low-level jobs but aren 't suited for really important or responsible positions."
 - Fact: People with mental illnesses, like everyone else, have the potential to work at any level depending on their own abilities, experience and motivation.



Major mental illness



- Personal histories lost, forgotten
- Difficulty organizing thoughts
- Trouble paying attention
- Anxious

Major Mental illness

- Staff, others have anxiety around them
- All behavior is interpreted as being related to mental illness

- Few, if any, family connections remain
- Limited reservoir of resources to bolster self-esteem

Limited, if any, social network

Common Terms

- Psychosis
- Hallucinations
- Delusions
- Disorganized thinking
- Disorientation

- Affect/Mood
 - Lability
- Pressured speech
- Neurovegetative

Tardive dyskinesia

Schizophrenia

- Usually starts in 20's, may begin after 40
- Delusions
- Hallucinations
- Disorganized thinking
 - "Loosening of associations"
- Disorganized behavior

- Social withdrawal
- Lack of drive or initiative, apathy
- Emotional unresponsiveness, flat affect

Schizophrenia

- Medication
 - Antipsychotics

- Psychosocial
 - Family education
 - CBT
 - Coordination

- Rehabilitation
 - Job
 - Life skills
 - Self-management
 - Recovery

DEMENTIA

Reversible

Irreversible

Depression

Degenerative Non-degenerative

Adverse drug reactions

Alzheimer's Disease

Vascular (MID)



Dementia

- Amnesia
- Anomia
- Agnosia
- Aphasia
- Apraxia

- Treatment
 - Medication
 - Caregiver support
 - Understanding behavior



- "I feel blue"
- "I feel tired all the time"
- "Nothing matters"

- "I don't enjoy things anymore"
- "I don't want to live anymore"
- "I want to kill myself"



- Sad mood, affect
- Anxiety, Irritability
- Low energy
- Poor appetite
- Poor sleep
- Poor concentration

- Loss of interest, pleasure
- Slow to answer questions
- Forgetfulness
- Move slowly



Pacing, hand-wringing

Hopelessness

Sitting quietly in corner

Guilt

Unkempt appearance, self-neglect Thoughts of death or suicide

Weight loss

Pessimism

- Medications
 - Antidepressants
 - Antipsychotics
- Therapy
 - Cognitive-behavioral
 - Interpersonal
 - Recovery

Mania

Euphoria,expansiveness

Irritability

→ ↑ sex drive

Interest in multiple projects

↓ need for sleep

Grandiosity

Mania

- Pressured speech
- Infectious humor
- Lability of affect
- Disorganized thinking
 - "flight of ideas"
 - Puns, word play, rhyming

Mania

- Treatment
- Medications
 - Mood stabilizers
- Recovery
- Illness self management

Anxiety

Anxiety

Fear

Avoidance

- Unease
 - Generalized
 - Specific
- Phobias:
 - Of social situations
 - Of open spaces
 - Of heights

Anxiety

Panic

Unexpected attacks

Worry about recurrence

Stress

^Arousal

- Acute

Post traumatic

Flashbacks

Anxiety

- Medications
 - SSRIs
 - (Benzodiazepines)

Cognitive behavioral therapy

Personality Disorders

- Personality
 - We all have one

- Way of being in the world
- Patterns which endure

- Disorder
 - Not working (maladaptive)
 - Inflexible

Cause significant distress

Drug Abuse

Continued use despite negative consequences

- Alcohol
 - "The disease that tells you you don't have it"
- Stimulants
- Marijuana
- Prescription drugs
 - Benzo's
- Heroin

Co-Occurring Disorders

- physical safety
- overall health risks
- ↑ impairment of life skills
- ↓ chances for successful treatment

all of which contribute to worse stigma

The Ombuds ToolKit

- You
 - Optimism
 - Conviction/Hope
 - Energy
 - Knowledge
 - Communication skills
- Medication Pamphlet

Recovery Workbooks

AntiStigma "Press Kit"

- List of resources
 - national
 - local

- talking to residents who have
 - Depression
 - Psychosis
 - Difficult personalities
 - PTSD
 - Substance Abuse Disorders
 - Severe Anxiety

- Anxious around other people
- Tentative around other people
- Difficulty organizing thoughts
- Trouble paying attention
- Movement disorders

What helps

- Active listening
- Empathy/Hope
- "I know you feel this way now, but you won't always"
- Engage"Come towith

me today"

What doesn't

- False cheer
 - » "Its not so bad"
 - » "Cheer up"
- Personal philosophy
 - » "There are people here worse off than you"



- Use gestures and visual cues or aids
 - Do not use gestures which threaten
- Communicate often
 - Avoid a constant stream

Use the same words

■ Take care with touch

- All behavior has meaning
- Attempt to communicate
 - Express a need or a feeling:
- Effect a change Start or Stop!
- Easier to change ours than others
- Whose problem is it?

Agitation

- Slapping thighs
- Clapping
- Yelling
- Screaming

- Self-referred
 - -Something is wrong with me

- Do something!

Agitation

- Common causes
 - Pain
 - Constipation
 - Discomfort
 - Infection
 - Drugs
 - Hearing loss

Make sense of the communication

Address the underlying problem

Aggression

- Hitting out
- Kicking
- Pinching
- Biting
- Threatening
- Swearing

Other referred

Something is wrong with you

STOP! Leave me alone

Aggression

- Common causes
 - Fear
 - Anxiety
 - Frustration
 - Medications
 - Sensory loss
 - Crowded or noisy environments
 - Abrupt, tense or impatient staff

What helps?

- Making sense of the communication
- Address the underlying problem
- Stop doing what you're doing
- Back away

- Stay calm
- Distract

Communicate in soft, low voice

Give directions slowly, one at a time

ISOLATION

- Personality
- Paranoia
- Sensory loss
- Depression
- Substance Abuse

Medications "Typical" Antipsychotics

- Target
 - hallucinations, delusions, disorganized thoughts and behavior
- Side effects
 - dry mouth, blurred vision, constipation, drowsiness and dizziness
 - Stiffness, drooling, shuffling gait, tremor
 - Slowing of thoughts, movements, sedation
- Common drugs
 - Thorazine, haldol, prolixin, stelazine, mellaril
 - Haldol, Prolixin, long-acting injections

Medications "Atypical" Antipsychotics

- Target
 - hallucinations, delusions, disorganized thoughts and behavior PLUS withdrawal, apathy, self-neglect
- Side effects:
 - weight gain!!!!!!! Sedation
 - At high doses, similar to typicals
- Common names
 - clozapine (clozaril), risperidone (risperdol), olanzapine (zyprexa), quetiapine (seroquel), ziprasidone (geodon)

Other Medication Side Effects

- Incontinence
- Urinary retention
- Constipation
- Unsteady gait
- Falls

■ ↑ Disorientation

■ ↓ Attention

Confusion ↑

Medications Antidepressants

- SSRIs
 - Target low mood, neurovegetative symptoms

- Side effects
 - sexual dysfunction, nausea, headache

 prolixin, sertraline (Zoloft), citalopram (celexa), paroxitene (paxil)

Medications Mood stabilizers

- Target
 - extreme highs and lows
 - impulsivity
- Side effects
 - tremor, weight gain
 - sedation

- Types
 - Lithium
 - Anticonvulsants
 - » depakoate, tegretol, neurontin
 - Olanzapine

Medications

- What inspires some people to stay on medication?
 - Being heard
 - » Partners in care
 - Liken mental illness to other medical problems
 - Support and information

Medications

Questions to ask

- 1. How will this help me?
- 2. What specific symptoms can this help?
- 3. What is the name of this medication?
- 4. What are the risks and benefits?
- 5. What are the most significant advantages?
- 6. How long will it take me to feel the effects?
- 7. How will I know I am experiencing a side effect?

Recovery

A way of living to make the most out of life

Recovery

- "... the act of gaining and taking back hope, personal identity and abilities – from loss due to disorder, injury, or submission to powerlessness.
- It is also a taking back of trust in one's own thoughts and choices so as to restore mental, emotional, social and biological order. It may be lifelong, intermittent, or shortterm."
- Public Health Model for the Recovery of Adult Mental Health was developed by Dornan and colleagues (2000)



Recovery

The ability to have hope

Trust my own thoughts

Enjoy the environment

Feel alert and alive

Elements

- Internal factors
 - Hope is the central theme
- Self-managed care
- External factors
- Empowerment



Language of recovery

Providers talk about "compliance" and "treatment resistant"

Consumers talk about "choice" and "right to refuse"

- partnership of equals
 - between clinician and client
 - between traditional and alternative services

{||||

The language of recovery

- "I just accept them, the real person. Then they will present more and more of themselves to you."
- Of paramount importance is
 - the belief in the person's capacity to recover
 - willingness to be clear, honest and informative
 - desire to learn from each individual what they feel, think and want
 - an ability to use this information in the manner most helpful to that person

Interventions

- Treatment
 - alleviating symptoms and distress
- Crisis intervention
 - controlling and resolving critical or dangerous problems
- Case management
 - obtaining the services clients need and want
- Rehabilitation
 - developing clients' skills and supports related to clients' goals – role functioning

Interventions

- Enrichment
 - engaging clients in fulfilling and satisfying activities
- Rights protection
 - advocating to uphold one's rights
- Basic support
 - providing the people, places, and things clients need to survive
- Self-help
 - exercising a voice and a choice in one's life
- Wellness/prevention
 - promoting healthy lifestyles

<u>|||</u>

Exercise

- any kind of physical activity is a great idea
- some medications may cause fatigue and weight gain
 - regular physical activity can ultimately decrease the sedation effects and weight gain
 - people with schizophrenia may avoid social interactions at gyms or in exercise classes
- exercise offers an opportunity to be with other people without having to depend on verbal communication

Exercise

- Find a supportive environment
- Work out in a safe place
- Enlist the support of family and physician
 - Even individuals who are working out by themselves should find someone they can talk with about their routine

National Alliance for the Mentally III (NAMI)
 1-800-950-NAMI
 www.nami.org

 National Alliance for Research on Schizophrenia and Depression (NARSAD) 1-800-829-8289 www.narsad.org

American Association of People with Disabilities
 1-800-840-8844
 1819 H Street, Northwest, Suite 330
 Washington, DC 20006
 Website: http://www.aapd-dc.org

- HUD Housing Discrimination Hotline 1-800-669-9777
- National Institute of Mental Health 301-443-4513 www.nimh.nih.gov

National Mental Health Association (NMHA)
 1-800-969-6642
 1021 Prince Street
 Alexandria, VA 22314-2971
 Website: http://www.nmha.org/

National Resource Center on Homelessness and Mental Illness
 1-800-444-7415
 262 Delaware Avenue
 Delmar, NY 12054-1123

 National Clearinghouse for Alcohol and Drug Information 1-800-729-6686

PO Box 2345

Rockville, MD 20847-2345

Website: http://www.health.org/

National Depressive and Manic-Depressive Association

1-800-82-NDMDA (1-800-826-3632)

730 North Franklin Street, Suite 501

Chicago, IL 60610-3526

Website: http://www.ndmda.org/

'Press' Kit

Real People Who Made and Make Real
 Contributions —

Despite Mental Illness

Resources/ACES

- Troy, NY
 Northeast Career Planning
 Maureen Melia and Kiki Garg 518-273-0818
- Stone Ridge, NY
 Ulster County Community College
 Sandra Bollin 914-687-5073
- Albany, NY
 Northeast Career Planning
 Cristin Sullivan 518-438-3445