



What's in your Travel Kit?

Helping Children and Families to Navigate
the Winding Road to Recovery

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BART'S PLACE:

Bringing All Relatives Together

at Northcoast Behavioral Healthcare
Cleveland Campus





What is BART's Place?

- A program that provides
 - Education, Information & Support to minor age children whose relative has a mental illness.
 - Feedback (to families and Tx teams).
 - Multidisciplinary team involvement.
- A physical space
 - Child-friendly environment

Guiding Principles

I. Recovery:

1. A process (not a cure)
2. Collaborative and patient directed
3. Empowering



“Recovery involves a way of living that allows individuals to move beyond illness in creating a meaningful and satisfying life.”

Diane Marsh (2001)

Guiding Principles

II. Resilience – “...characterized by good outcomes in spite of serious threats to adaptation or development” (Masten, 2001).

1. Strengths and Limitations (a balanced view)
2. Constructive adaptation (what has worked?)
3. Resources (person and situational)

You cannot prevent the birds of
sorrow from flying over your head,
but you can prevent them from
building nests in your hair.



Chinese Proverb



Comprehensive BART Services

1. Inpatient family sessions

2. Inpatient psychoeducation groups

- Focus on communicating with family members about mental illness issues.

3. Consultation to Treatment Team

- Individual cases: parenting issues, pregnancy, loss of custody.

BART Outpatient

4. Outpatient KidSupport groups

- Coordinated with NAMI

5. Guest speaking engagements

- Schools
- Churches
- Healthcare systems

What is NAMI?

- National and Local organization

- Information
- Support
- Education
- Advocacy



What is it like to have a relative with serious mental illness?

A. Family Burden

1. Objective
2. Subjective



What is it like to have a relative with serious mental illness?

A. Family Burden

1. Objective (examples)
 - Financial
 - Daily hassles/sx behavior
 - Change of caregivers
 - Periodic crises
 - Parents unavailable
 - Possible exposure to violence
 - Family focus on illness



What is it like to have a relative with serious mental illness?

A. Family Burden

2. Subjective (examples)

- Grief
- Chronic Sorrow
- Emotional roller-coaster
- Empathetic pain and guilt



Top challenges or “shared concerns” cited in research

1. Providing care for the ill relative (94%)
2. Family disruptions (83%)
3. Difficulty balancing family and personal needs (81%)
4. Realization that own needs have not been met (79%)

(From Marsh & Dickens, 1997- percentage of participants who felt this concern at least sometimes).

Top challenges observed/described while ill relative is in the hospital

Objective

- Periodic Crises
 - Difficult to make plans
 - Anticipatory anxiety
- Family focus on illness... so parents are unavailable
 - Dinner conversations
 - Spare time in appointments
- Finances

Top challenges observed/described while ill relative is in the hospital

Subjective

- Emotional roller coaster
- Revolving guilt, anger, and fear
- Grief

In the dark soul of the night, I grieve for all of us: for the anguish of the past and the present, and for the uncertainty of the future.

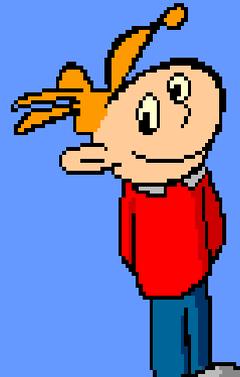
Anonymous mother,
Marsh, 2001 (p.22)

Top challenges observed/described in outpatient, supportive settings

- Unrealistic expectations-
 - Why aren't they better yet?
- Choices and fears
 - Should I bring it up or not?
 - Will I get the illness?
- Responsibility vs. Control
- How to handle the holidays
- Change in the relationship
 - They are not the same person.

Children and the impact of a psychiatric crisis

How does a child react when a parent is hospitalized?



Immediate impact on children: Hospitalization of a parent

- **Anxiety/Distress** (Marsh & Dickens, 1997; Shachnow, 1987; Sivec et al, 2004)
 - General anxiety-
 - 26% of children on the MASC during a parent's hospitalization (Sivec, Masterson, Katz, Russ, 2003)
 - Separation problems:
 - 18% of children on the MASC during a parent's hospitalization (Sivec, et al., 2003).
 - 51% of participants over their lifetime (Marsh & Dickens, 1997).

Features of negative reactions by age to inpatient hospitalization

- Pre-teens (< 12 yrs)
 - Sleep disturbance
 - Diminished appetite
 - More clinging
 - Crying near bed-time
 - Social withdrawal
 - Problems with attention and learning
- Teens (12 and up)
 - Noticeable drop in school performance (12/14 youth).
 - Sleep disturbance
 - Social Withdrawal and embarrassment.

Shachnow, 1987

Long term risks

In general and over time, children of parents with SMI are at increased risk for:

1. Developing mental illness.
2. Having adjustment problems.
3. Experiencing problems in relationships.

(Feldman, et al., 1987; Marsh, 1997)

What do the experts recommend?

- Information: Intervention/prevention programs to provide age-appropriate information to children.
 - Include children in family and/or individualized treatment.
- Resources: Programs designed to support resilience and strengthen coping skills in children.
- Support: Stable caregivers are essential.
 - Permission and encouragement to talk and inquire.

What about Coping?

Coping refers to “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person

(Lazarus & Folkman, 1984, p. 141).”

Contrasting coping reactions

(Shachnow, 1987)

- Compromised
 - Age 5 or less at onset
 - Below average IQ
 - Mother is the ill parent
 - Chronic illness, poor premorbid adjustment
 - Parental pathology that incorporates the child
 - No sibs
 - Adult caregiver absent
- Effective Coping
 - Age > 8 at onset
 - Above average IQ
 - Father is ill or mother after several years of “good enough” parenting
 - Acute illness, with good pre-morbid adjustment
 - Adult caregiver present

Understanding Coping Involves:

Assessment at the individual level-

- What is the stressor?
- How is it being appraised?
- What strategies does the person have in his/her repertoire?
 - *Not:* How did you cope with X?

Broad Categories of Coping:

- Addressing the Problem Directly

- Active Coping (Ayers et al., 1996)
- Primary Control Coping (Connor-Smith et al., 2000)

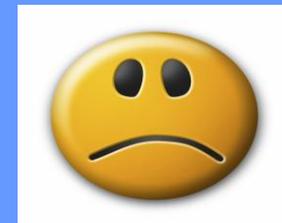


- Addressing How You Feel

- Support Seeking, Distraction Coping (Ayers et al., 1996)
- Secondary Control Coping (Connor-Smith et al., 2000)

- Ignoring The Problem

- Avoidant Coping (Ayers et al., 1996)
- Disengagement Coping (Connor-Smith et al., 2000)



Addressing The Problem Directly

Categories:

- Constructive problem solving approach
- Identify Specific solutions

Examples:

- Parent/patient overreacts to stress. What are ways to lower stressors?
- Do dishes before bed
- Fix the wall

Addressing How You Feel

Categories

- Seeking Understanding
- Positive Cognitive Restructuring

Examples

- Read about mental illness
- Who's responsible for what?
 - "I didn't cause the illness"
 - "I have needs too"

Addressing How You Feel

Categories

- Social support
- Physical Release of emotions
- Stress management

Examples

- Tell someone how you're feeling (uncle, teacher, counselor)
- Jogging, shoot baskets, ride bikes, writing/drawing
- Relaxation skills, deep breathing, positive imagery

Ignoring the Problem

Categories:

Examples:

Avoidant Actions

Refuse to visit
hospital

Stay away from
home

Cognitive Avoidance/Denial

Push thought out of
mind

Tell self "It's not really
happening"

Ways to assess coping and resilience

- Standard psychological tests
- Specialized tests
- Clinical interview strategies

What Works Best?

- In general, better health outcomes associated with fixing the problem & fixing feelings than with ignoring the problem

(Compas et al., 2001; Jaser et al., 2005)

What Works Best?

- Most important: To have a variety of approaches available so there's always a back-up plan (Curry & Russ, 1985)



"According to the charts, it should be all clear sailing after this."

Let's see an example

Video

Coping challenges

Matching coping behavior
to challenge or stressor

Challenge → Coping

- **Caregiving responsibility for parent**
- Address the problem:
Identify appropriate roles (child-adult) and tasks.
- Address your feelings:
Seek support/help (fix feelings)

Challenge → Coping

- **Periodic Crises**
- Address the problem
 - Plans and back-up plans.
 - Review effective solutions to previous crises.
 - Work together
 - Build in “down time” as part of schedule.

Challenge → Coping

- **Over-focused on illness... parents unavailable**
- Address the problem:
 - Schedule times for illness discussion and times for other topics
- Address how you feel:
 - Social support-
 - Involve Big-brother; Big Sister
 - KIDSUPPORT

Challenge → Coping

- **Grief**
 - Address your feelings
 - Seek understanding (realization that relationship has changed).
 - Educate self regarding mental illness and grief
 - Seek support- counselor and friends
 - Allow self to grieve

Stages of grieving

(a family members mental illness)

- Denial and isolation
- Anger
- Depression
- Bargaining
- Acceptance

(Kubler-Ross, 1969; see also Marsh, 2001;
Spaniol & Jung, 1987)

Challenge → Coping

- **Revolving guilt, anger, and fear**
- **Emotional roller coaster**
- Address your feelings:
 - Cognitive restructuring
 - Did not cause illness
 - I have needs and limits
 - Stress management
 - Deep breathing/relax
 - Exercise
 - Journaling
 - Seek support
 - Peer or counselor

Challenge → Coping

- **Unrealistic expectations**
- Address the problem:
 - Educate self regarding recovery
- Address your feelings:
 - Modify thinking

Challenge → Coping

- **Choices and fears**
 - Should I talk about it?
 - Will I get ill?
- Address the problems
- Address your feelings

Challenge → Coping

- **Responsibility vs. Control**
- Address the Problem
- Address your Feelings

Challenge → Coping

- **How to handle the holidays?**

Address the Problem:

Address your feelings:

Other ways to address the problem:

- Problem: mother criticized or verbally abused child at times.
 - Constructive Problem solving: what can I do when this happens? What steps can I take to help me?
 - Direct solutions: Ask her to stop. Tell her she is going to leave. Leave situation if necessary and call support person.

Other ways to address the feelings

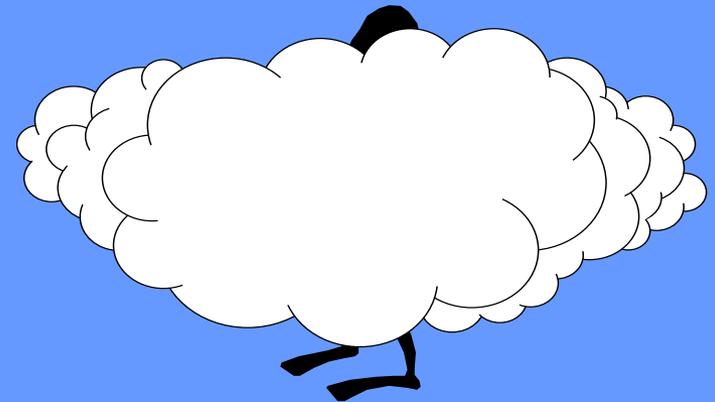
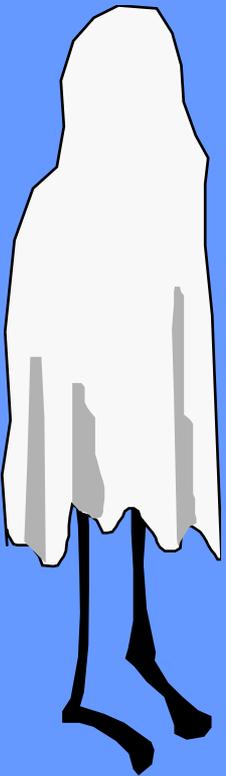
- “My behavior caused my mother’s violence”
 - Cognitive restructuring:
 - Education about mental illness and reframing the problem
 - Clarifying responsibility
 - Guilt: “name it, frame it, tame it”.

Addressing feelings

- Identified supports: church youth group, grandmother eventually adopted her; friends
- Releasing emotions: writing and talking with boyfriend.
- Stress Management: Prayer/meditation; positive imagery work- future goals

What about avoidance?

What happens if you ignore the
problem?



The price of avoidance

“I often felt as if I were in the middle of a game for which no one bothered to explain the rules. Gradually, I froze up emotionally. Life lost its color, and I lost my spontaneity and joy.”

Marsh & Dickens, 1997

The price of avoidance

“I have spent my life trying to run away from this problem. Feeling guilty and helpless, the unending sorrow for not being able to help. I have not felt entitled to be happy most of my adult life.”

-Anonymous

The price of avoidance

- Problem: mother's depression and alcoholism. GM enabling.
- Gma dies, child has school problems.
- Family could not change Gma's enabling behavior; mother's situation worsens.
- Child does not speak up; covers for his mother, becomes very passive, school and social behavior deteriorate.

The alternatives to avoidance

- When child was younger, involve professional and attempt a family intervention with the mother.
- Ongoing work with grandmother- individual therapy, NAMI education groups
- Family education and Alanon groups

The alternatives to avoidance

- For the child
 - Identify a primary caretaker
 - Involve child in counseling (assess and intervene regarding coping methods)
 - Connect child and family to community resources

Child and family coping is intertwined

- Children learn coping patterns from family members.
- When teaching coping skills, must involve available adult caretakers.

Child and family coping is intertwined

- First priority: Identify reliable adult caregiver.
- Assess strengths/weaknesses of family
- Individualize the teaching of coping skills within the context of the family.

Bring and use your travel kit

T- talk

R- respect

A- accept

V- virtues

E- energy

L- listen

K- knowledge

I- individuality

T- time

“Wisdom is knowing what to do next, skill is knowing how to do it, and virtue is doing it.”

David Starr Jordan

Thank you



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