MEND Treatment Manual

Working with Children and Adolescents with Complex Medical Conditions

© No contents of this document should be reproduced or distributed without written authorization from Daniel Tapanes, DMFT, LMFT - Behavioral Health Institute, Loma Linda University.

Authors: Daniel Tapanes, DMFT, LMFT, Jackie Williams-Reade, PhD, LMFT, Deepti Vaswani, PsyD, Brian Distelberg, PhD, Susanne Montgomery, MPH, PhD
Table of Contents

INTRODUCTION OF MEND ................................................................. 6
  General Overview ........................................................................... 6
  Targeted Outcomes ........................................................................ 7
  Background and Rationale ............................................................ 7
  Uniqueness of MEND .................................................................... 8
  Focus of Treatment ......................................................................... 10

GUIDING PRINCIPLES OF MEND ....................................................... 11
  Ecological Influences on a Child’s Stress Response ....................... 11
  Interoception ................................................................................ 15
  Shifting Patterns through Shifting Meaning .................................. 16

FORMAT & STRUCTURE ...................................................................... 19
  Intakes and Assessments .............................................................. 19
  Daily Schedule ............................................................................ 19
    First Hour: Check-in and Peer Group .......................................... 20
    Second Hour: Therapeutic Activities .......................................... 22
    Third Hour: Multi-Family Group ................................................. 22
    Individual and Family Therapy Session ...................................... 23
    Aftercare .................................................................................. 23

THE MEND TEAM ............................................................................ 24

PHASES OF TREATMENT .................................................................. 24

PHASE I – ORIENTATION, ASSESSMENT, AND LANGUAGE ............ 28
  Step One: Orientation and Development of Therapeutic
  Relationship ................................................................................ 29
  Patient and Family Buy-In .......................................................... 31
  Integrating Patient into Peer Group ............................................. 32
  Peer Positions ............................................................................. 34
  Step Two: Biopsychosocial Assessment ....................................... 36
MEND: Mastering Each New Direction

Illness Meaning and Coauthored Stories............................................37
Stress Responses ..............................................................................43
Development .....................................................................................47
Systemic Functioning of the Family....................................................48
Identification of maladaptive needs directed behavior (power)............49
Step Three: Language Learning and Teaching.................................51
Language Learning.............................................................................52
Language Teaching and Shaping.........................................................59

PHASE II – INTROSPECTION AND CONGRUENCE...............................62
Step One: Mind-body Connections ....................................................63
Interoception and Introspection.........................................................64
Identify and Access Unconscious Processes.......................................66
Step Two: Language Development ....................................................68
Burden Identification.........................................................................70
Voice Recognition.............................................................................71
Practice Using Voice.........................................................................72
Step Three: Congruence.....................................................................74
Developing Congruence in All Domains............................................75
Continued Connection of Emotions with Psychogenic Responses.....76
Separate Psychosomatic Issues.........................................................77
Step Four: Meaning Response Testing...............................................80
Testing Meaning Responses.............................................................82
Psychogenic Regression Process.......................................................87
Process Buy-In..................................................................................89
Step Five: Systemic Adjustment........................................................89
Identification of Power.....................................................................90
Therapist-Family Collaboration.........................................................91
Parent Support....................................................................................93
Identify Guilt and Shame Processes in Parenting...............................94

PHASE III – MEANING AND EXPRESSION .........................................97
### MEND: Mastering Each New Direction

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step One: Creating Changes in Meaning</td>
<td>98</td>
</tr>
<tr>
<td>Meaning Responses and Change</td>
<td>100</td>
</tr>
<tr>
<td>Continued Language Development</td>
<td>103</td>
</tr>
<tr>
<td>Testing Response Integration</td>
<td>105</td>
</tr>
<tr>
<td>Physiological Response Changes</td>
<td>110</td>
</tr>
<tr>
<td>Step Two: Systemic Acceptance of Change</td>
<td>110</td>
</tr>
<tr>
<td>Predict and Prepare</td>
<td>111</td>
</tr>
<tr>
<td>Test the Family for Systemic Changes</td>
<td>113</td>
</tr>
<tr>
<td>Systemic Buy-In and Integration</td>
<td>114</td>
</tr>
<tr>
<td>Reorienting Parent Identity</td>
<td>115</td>
</tr>
<tr>
<td><strong>PHASE IV – CHANGE GENERALIZATION AND REINTEGRATION</strong></td>
<td>117</td>
</tr>
<tr>
<td>Step One: Changes beyond the individual and system</td>
<td>117</td>
</tr>
<tr>
<td>Set-Up Challenge Responses</td>
<td>120</td>
</tr>
<tr>
<td>Adjustment and Reintegration into Healthy Development</td>
<td>123</td>
</tr>
<tr>
<td>Step Two: Identification and integration of supportive services</td>
<td>130</td>
</tr>
<tr>
<td>Social</td>
<td>130</td>
</tr>
<tr>
<td>Family</td>
<td>131</td>
</tr>
<tr>
<td>Academic</td>
<td>132</td>
</tr>
<tr>
<td>Step Three: Graduation</td>
<td>133</td>
</tr>
<tr>
<td>Multi-family Family Group Reflection</td>
<td>134</td>
</tr>
<tr>
<td><strong>Appendix</strong></td>
<td>137</td>
</tr>
<tr>
<td>7 &amp; 7</td>
<td>138</td>
</tr>
<tr>
<td>A Love Letter… The Complete Truth</td>
<td>142</td>
</tr>
<tr>
<td>Body Image</td>
<td>143</td>
</tr>
<tr>
<td>Diagram</td>
<td>145</td>
</tr>
<tr>
<td>Executive Functions</td>
<td>146</td>
</tr>
<tr>
<td>Dorsal Vagal Regulation</td>
<td>147</td>
</tr>
<tr>
<td>Child or Adolescent Meaning</td>
<td>148</td>
</tr>
<tr>
<td>Family Tree</td>
<td>149</td>
</tr>
<tr>
<td>Forethought</td>
<td>151</td>
</tr>
</tbody>
</table>
This document can be found online at mendmanual.com.
INTRODUCTION OF MEND

General Overview

The purpose of this manual is to offer an overview of the general structure and critical elements of Mastering Each New Direction (MEND) Therapy as it applies to pediatric patients ages 8-18. MEND is an intensive outpatient program designed to treat patients who are experiencing the emotional struggles of dealing with a chronic illness. Most often patients are referred to MEND through their specialty care team in order to address treatment regimen adherence problems. MEND is based on a family systems orientation in conjunction with a biopsychosocial framework to address the unique mental health needs of this population through individual, group, and family therapy processes.

MEND approaches illness management issues with the understanding that adhering to a treatment regimen, which often includes taking medication, altering lifestyle, and treatment side effects, is often perceived by the pediatric patient as being in direct conflict with their desire to be normal and meet age-appropriate developmental milestones. This conflict between treatment adherence and being “normal” is often a key factor that negatively impacts their illness management and health-related quality of life. To address this, MEND targets
individual and family patterns of coping and stress response in order to address the meaning-based barriers that inhibit treatment adherence and appropriate illness adjustment. The desired outcome of MEND is to improve treatment adherence, overall quality of life, and disease specific outcomes.

**Targeted Outcomes**

MEND targets first and second order outcomes for both patients and their family members. The first order outcomes are specific to a child’s disease and center around treatment adherence while second order outcomes include addressing the emotional struggles and stress associated with the pediatric patient’s illness as well as the primary caregiver(s) and sibling(s) responses. The second order outcome for MEND families is the integration of more facilitative and adaptive responses to illness within both the individual, family system, and broader social context (peers and academic setting). Eliciting these changes in the family system provides sustainable, long-term improvements in both physical disease outcomes and family functioning.

**Background and Rationale**

Maintaining emotional health and balance can be a daunting task in the face of chronic illness. Children who experience complex or chronic illness are often subject to painful treatments with uncomfortable side effects, disruptions in their
social and academic schedules, and changes in the overall functioning of their families. Significant changes in socioeconomics are also common as there are significant costs of time and money when caring for a chronically ill child. With multiple medical appointments and hospitalizations, it becomes difficult for both parents to work, or a single parent to work at all. Siblings often experience added responsibilities due to these economic stressors and decreased functioning in the child who is ill. Both the ill child and their siblings often miss aspects of childhood under the strain of the added responsibility experienced in the system attempting to manage chronic illness. The family system may react to some or all of these responses in ways that may negatively impact the patient’s belief about the illness and themselves. The chronically ill child may interpret all of this added stress as being their fault and feel varying degrees of fear, anger, guilt and shame. These illness-related stressors can pile up and negatively impact a child and his/her family members’ ability to cope and ultimately lead to negative effects on their physical health, including non-adherence to medical treatment.

Uniqueness of MEND

MEND differs from traditional treatments in that MEND addresses long-term changes in the family system through challenging negative meaning processes held by both patients and family members in response to illness. Because of the stress
experienced by patients with chronic illness and their family members, it is imperative to understand and address patterns of coping with stress that may be constraining and prevent the family and the child from adapting to the illness. In addition, MEND address the physiological impact of illness that result from the illness-related stressors which cause the body to produce chemical responses that have immunosuppressive (weakening of the immune system) properties, affect cognitive function, and cause psychological distress. Oftentimes families referred to MEND have developed maladaptive stress and coping patterns that prevent the family and the child from adapting to the impact of the illness. These patterns of coping with stress may be constraining and prevent the family and the child from adapting to the illness.

In response, MEND uses family systems-informed interventions to help patients and family members express their needs and concerns regarding the child’s illness, increase their ability to listen and respond to the needs of their physical body in a way that is adaptive, and raise their awareness of their individual stress response and ways to cope and address their stressors. Through the MEND program, patients discover new meanings and perceptions regarding their illness and take more control, ask for needed support, and access appropriate resources which lead to increased compliance-related behaviors and improved overall health-related quality of life.
Focus of Treatment

The MEND program provides improvement in stress and coping responses as well as treatment adherence and disease outcomes through targeting seven specific areas of the illness experience for patients and family members:

1. Anxiety: Worry and fear about their illness, life expectancy, and academic/social limitations.
2. Body Image: Adjusting to bodily changes due to medication and treatment side effects.
3. Compliance: Difficulty adhering to medication management, diet, exercise, or physical restrictions.
4. Depression: Sadness and hopelessness related to a life with limitations, “survivors’ guilt,” missed school days and contact with friends and peers.
5. Family Issues: For children, rebellion or resistance with medical regimens; for parents struggling with feelings of fear, shame or guilt that affects family relationships. For siblings, feelings of “survivor guilt” and/or issues of jealousy regarding the attention their sibling receives on account of being ill.
6. Grief and Loss: Coming to terms with the limitations of their body and potential longevity.
7. Self-esteem: Not feeling normal due to medications and diet and physical restrictions.
GUIDING PRINCIPLES OF MEND

In an effort to shift maladaptive coping patterns of each family member, MEND employs three guiding principles: 1) the ecological evaluation of influences on a child’s stress response pattern, 2) interoception, introspection and 3) shifting patterns through shifting meaning.

Ecological Influences on a Child’s Stress Response

For many chronically ill children and their families, the stressors associated with disease can trigger the body’s production of chemical responses to stress and fear that have immunosuppressive properties, influence cognitive and integrative abilities, and cause psychological issues. For the pediatric patient, having an illness can create a sense of isolation, desperation, and a feeling of looking and being different from their healthier, “normal” peers. In response to this stress, the child may display decreased cognition and integrative functioning, and compliance with medical treatment regimens can be significantly compromised. High levels of stress within themselves and their family unit can override even the most basic of healthy choices such as nutrition, self-monitoring, and medication which negatively affects their health outcomes. The MEND treatment focus is to decrease these stress responses, thereby enhancing the cognitive and integrative abilities of the patient.

Create a relationship with the child not the illness ...
MEND recognizes that patterns of coping in response to stress are not simply experienced by the individual (child), but are interdependent with the parent-child relationship, larger family system, and peer networks. Because of this, MEND works to produce sustainable improvement in stress responses on three ecological levels of influence: family, social, and academic. The stress associated with the child’s illness will manifest itself in various ways based on the meanings by which the chronically ill patient and their family systems function in response to the illness. Similarly, academic, familial, and social settings are all subject to different stressors within the context of illness. These stressors can influence cognitive integration and use of information which can severely impact self-management of illness. Part of the process of MEND is to identify how individuals in these various ecological systems create and/or coauthor illness meanings. Once learned, these meanings become the basis for intervention by the MEND therapist in order to help patients and family members create more positive illness meanings which promote facilitative coping patterns.

Family

The patient’s family system has a significant influence on how the meaning of illness is created. Patients and family members participate in a coauthoring process by which information about the illness is taken in and ascribed meaning. Children look to their primary caregivers to provide information about what it means to be ill and
appropriate ways to manage an illness. As primary caregivers to a child with a chronic illness, parents or guardians may experience significant physical, emotional, and financial stress which may result in them sending negative emotional messages to their child, including feelings of being burdened or guilt about their child not being “normal.” These messages can affirm the child’s negative internal thoughts of being broken or a burden to the family. Thus, a chronically ill child’s attempts to understanding the meaning of their illness is coauthored by the members of their family system.

Social

The same processes take place in other contexts for the chronically ill child and their family. How other individuals in medical, educational, and social contexts respond to the child and family can also influence and coauthor illness meanings. For instance, in social situations the ill child may be given special accommodations to reduce discrimination or increase opportunities for engagement. These special accommodations can inadvertently give these children the feeling of being different and limited. Social acceptance is often the primary developmental drive for children at this stage, and, for the chronically ill child, socialization is often compromised due to significantly decreased peer interaction because of the inability to attend school regularly or participate in extracurricular activities. It should be noted that assessing for social development of the MEND patient can be deceiving as the patient may initially present as well
developed socially with a strong vocabulary. However, their advanced presentation is often due to the child interacting mainly with adults due to being in the hospital or at home unable to attend school. When the patient is integrated into the peer setting of the MEND therapy group, their social development can be accurately observed.

“As children develop, their brains "mirror" their parent's brain. In other words, the parent's own growth and development, or lack of those, impact the child's brain. As parents become more aware and emotionally healthy, their children reap the rewards and move toward health as well.”

**Academic**

The chronically ill child who is attending school for the first time or returning after treatment is often given allowances and limitations in order to function within the academic system, such as lightened class load, reduced homework, permission to not partake in certain activities, etc. Parents sometimes introduce additional allowances that are not medically necessary due to their own fears and anxieties regarding their child’s well-being, such as not being allowed to take the bus or stay late for extracurricular activities. These limitations further influence the child’s understanding of their academic abilities and identity.
Interoception

A central focus of MEND includes the patient’s mind-body connection. The mind-body connection is the inter-connected process by which the patient learns how their emotional and thought processes impact and are impacted by their physical body. Oftentimes, patients have significant physical and emotional disconnects from their body. Because their body has “failed” them, the child has learned to distance himself from the pain of the illness, the discomfort of the treatment, and the uncomfortable side effects. In terms of emotion, the child may distance himself from illness meanings which are laden with guilt and shame. This disconnect often results in patients being unaware of their physiological and emotional experiences. In order to address this disconnect, MEND teaches skills of interoception, which is the process of looking inward and attending to the internal responses of one’s body. Through identifying these internal emotional processes, the MEND patient can begin to gain an accurate sense of their overall well-being, both emotionally and physically.

Congruence

The primary mind-body connection focused on in MEND is the connection between psychological, cognitive and emotional processes with the Sympathetic Nervous System (SNS). The SNS is the system which triggers the biochemical and physiological changes brought about by a stress response. Paying attention to the physical cues of
the body, such as pain, tenseness, or changes in respiration, MEND patients begin to align information between their emotional state and physiological experience towards a more “congruent” state. MEND therapists use the term “congruent” to illuminate the connection between physical and emotional cues expressed by patients. An example of how a MEND therapist would use the term congruent can be seen in the following example. If a child verbalizes an emotion of happiness, but their nonverbal cues show stress or even frustration, the MEND therapist might point out this situation to the child and state that their words and the body are “incongruent”. Later on, when the child shows nonverbal cues that match what they are saying verbally, the therapist will point out that they are being “congruent.” Highlighting the process of being congruent gives the patient and family members a way to interact with each other and talk about responses to illness which they may have never had before. Once MEND patients learn the ability to accurately read their body’s responses to emotional processes, they can take that information and better understand and manage their mind-body connection thus maintaining mind-body congruence. As patients practice interoception and learn to become congruent, broader systemic changes can begin to occur.

**Shifting Patterns through Shifting Meaning**

Influences from various ecological levels impact both individual and family member
responses to illness in either facilitative or constraining ways depending on their meaning. The meaning the family gives to the illness can play a powerful role in a child’s development, stress response, and adaptation to illness. Because stress responses are directly influenced by illness beliefs and meanings, the MEND program emphasizes understanding and positively influencing the meanings the patient and family members’ hold regarding the illness. These meanings can be assessed through the stories told by patients and family members regarding the illness.

In the beginning of treatment, the MEND therapist assesses the language and coping processes used by the patient and family members in order to better understand the family’s meanings and subsequent behaviors related to coping with the illness. Oftentimes, the meanings perpetuate a maladaptive coping pattern within the family that exacerbates the stress experienced by patient and family members. For many chronically ill children, they understand their illness story in ways that place burdensome levels of responsibility or even shame onto them. In this case, the chronically ill child might feel that they are solely responsible for the stressors within the family such as: family relational stress, financial stress, parent’s feeling overwhelmed, and sibling(s) feeling like they receive less attention than the chronically ill child. These powerful illness stories are created and sustained through language, thus MEND uses language as a primary agent of change. Paying attention to the language and meaning each family has given to the
illness is a critical feature of the MEND process as these stories and meanings will be used to determine how to best intervene in the family system to bring about necessary changes and assess for appropriate progress throughout treatment.

These three principles: ecological evaluation of influences on a child’s stress response pattern, interoception, and shifting patterns through shifting meaning guide the conceptual framework of MEND and are continually addressed through the following format.
FORMAT & STRUCTURE

Intakes and Assessments

Prior to starting the program, each individual and their caregivers will be asked to attend an assessment and intake sessions. The assessment session is an in person appointment where the therapist performs a biopsychosocial assessment focused on the patient’s current medical, psychological and social needs and strengths. The nurse will also complete a standard medication check and head to toe physical health examine. If, after completing the assessment, the team determines that the individual could benefit from MEND they are instructed to attend an intake session.

Intake session begin with educational information for the patient and the caregiver, including the daily schedule and principles of MEND. This intake session will also include measures and assessments given as baseline data to be used for patient monitoring and quality assurance within the program.

Daily Schedule

MEND typically consists of three sessions a week for seven weeks, titrating down to two sessions per week for another week, and then graduating the first treatment day of the following week, for an average of 21 sessions. MEND patients then attend aftercare groups once a week for four weeks. The MEND treatment days are
Mondays, Wednesdays and Thursdays from 3:30pm to 6:30pm. Each treatment day lasts three hours, broken into three one-hour sessions: Hour 1: check-in process; Hour 2: peer group sessions; Hour 3: multi-family groups. Aftercare runs on Tuesdays for 90 minutes from 3:30 – 5:00pm. Outside of the regular three hour sessions, MEND patients may participate in family sessions and additional therapeutic activities detailed below.

<table>
<thead>
<tr>
<th>Hour 1</th>
<th>Check-in and Peer Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hour 2</td>
<td>Therapeutic Activity – Group or Individual (including individual therapy sessions, family therapy sessions, and parent education)</td>
</tr>
<tr>
<td>Hour 3</td>
<td>Multi-family session</td>
</tr>
</tbody>
</table>

In addition to the three hours below, the nurse team member will conduct physical health examinations and monitoring prior to the start of each day. The frequency of these evaluations varies depending on the individual’s severity and is set by the physician and team at the assessment. Also the physician will meet with the individual at least once per week to review medical conditions and goals.

**First Hour: Check-in and Peer Group**

During this first hour, the children discuss their progress in managing appropriate stress responses, their current level of stress, and disease-specific treatment adherence goals. Patients spend the first several minutes of each MEND session filling out the check-in assessment form which is designed to report and address multiple domains of
health, medication compliance, and emotional health. This tool was designed by the creator of MEND with input from various interdisciplinary team members. The survey is a self-report which covers the following four domains: general emotional state, compliance issues, experience of pain, and level of stress. The first domain measures the general emotional state of the patient on a 10-item Likert scale that includes the following areas: happiness, feelings of being loved, confidence, sadness, depression, anxiety and anger. The second domain addresses issues of compliance, which includes medication times, side effects, and hours of sleep. In addition, for diabetic patients, this section covers the last three blood sugar levels taken, any levels over 300 in the last twenty-four hours, and the last food eaten. The third domain is a pain scale with rankings from 1-10 for the overall quality of pain experienced. Also within this section is a front and back body silhouette where the patient can mark the anatomic locations of the pain or discomfort. The fourth domain is the Level of Stress Scale (LSS), which addresses stressful life perceptions, such as concerns about health, and social and familial stressors. Each patient completes his or her check-in survey sheet on each treatment day. Sheets are kept in the patient’s chart and used to track patient progress and program outcomes. Following this check-in time, the children move on to a group therapy process.
Second Hour: Therapeutic Activities

The second hour of the program day consists of therapeutic activities, which may include individual or family therapy and a peer group process. A typical peer group has eight to ten patients. The therapeutic tasks during this hour will focus on reported or observed markers from the patient’s check-in survey reporting or psychosocial history. Given the open enrollment of the program, the curriculum cycles through topics and activities that are relevant across all of the four phases. Although each day has a prescribed curriculum, all sessions contain activities focused on managing stress and identifying maladaptive stress response patterns using a combination of talk and art therapy techniques. While the children are in their peer group session with one of the therapists, parents are engaged in education and process groups with one of the other therapists from the MEND team.

Third Hour: Multi-Family Group

In the final hour of the session, the children and the parents come together for multi-family groups to address that day’s processes systemically. Often the assigned therapeutic activity of the day from the peer group is used as a process topic during this time. During one of the multi-family sessions, the parents meet with the MEND therapist in a group setting. During this hour the therapist and the parents work to deconstruct parental positions of shame and guilt, while identifying and installing leverage points for second
order or systemic changes. The other sessions are formatted as family activities geared to enhance systemic function.

**Individual and Family Therapy Session**

Outside of the regular three hour sessions, MEND patients may participate in additional individual and family therapy sessions. The necessity of this action is based on whether the therapist has requested a case consult with the specialty care team, if the parents have requested this action, or if the therapy team has concerns about the child or family not meeting the needed developmental milestones.

**Aftercare**

Aftercare is an essential part of the MEND program as it seeks to solidify phase four concepts outside the intense treatment schedule as patients and their families are now fully responsible for maintaining their new equilibrium. Aftercare is a 90 minute structure where the children and their parents are in separate groups for the first hour, then coming together for the last 30 minutes. The MEND therapist will check-in with the children and families, prompting the attendees to report on phase four concepts that inform the MEND therapist on the stability of second order change.
THE MEND TEAM

MEND is an interdisciplinary team consisting of multiple MEND therapists, a nurse and a physician. The MEND therapist is the focus of this manual and is the lead for the change desired in the MEND program. The nurse and physician are also critical members of the treatment team and together this group works directly with the patient’s referring medical team. This team meets weekly for case consultation and works together in same building and offices allowing for seamless communication day to day. The physician is mainly responsible for the overall health needs of the child, while the nurse conducts the initial and ongoing evaluations/assessments of the child’s physical health. While each discipline brings a certain focus to the overall treatment goals, all members of the team work together, through the principles laid out in the following chapters to achieve the MEND targeted goals.

PHASES OF TREATMENT

The MEND model of treatment includes four distinct phases which span from the initial assessment and continuing through the patient’s “graduation” (or successful completion) from the program. While the overall course of treatment is guided by the following four phases, it is important
to note that treatment often does not proceed in a linear manner and each patient and family will progress through each phase at their own pace.
### Phase I: Orientation, Assessment and Language

<table>
<thead>
<tr>
<th>Step One: Orientation and Development of Therapeutic Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>● <strong>Patient and Family Buy-In</strong> regarding rules, therapeutic process, and peer environment</td>
</tr>
<tr>
<td>● Integrating Patient into Peer Group</td>
</tr>
<tr>
<td>● Setting up Appropriate Peer Positions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step Two: Biopsychosocial Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>● <strong>Illness Meaning and Coauthored Stores</strong>: Understand the perceived meaning(s) of the patient’s illness</td>
</tr>
<tr>
<td>● <strong>Stress Responses</strong> of the patient in response to illness meaning</td>
</tr>
<tr>
<td>● <strong>Patient development</strong> (socially and psychologically) as a result of the illness</td>
</tr>
<tr>
<td>● <strong>Systemic Functioning of the Family</strong> and response to the patient’s illness meaning(s)</td>
</tr>
<tr>
<td>● <strong>Needs Directed Behavior (power)</strong> related to their illness</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step Three: Language Learning and Teaching</th>
</tr>
</thead>
<tbody>
<tr>
<td>● <strong>Language Learning</strong>: Learn a patient’s psychogenically congruent language</td>
</tr>
<tr>
<td>● <strong>Language Teaching/Shaping</strong>: Teaching language to patients in order to create a common language among patients, family members, and therapists</td>
</tr>
</tbody>
</table>

### Phase II: Introspection and Congruence

<table>
<thead>
<tr>
<th>Step One: Mind-body Connections</th>
</tr>
</thead>
<tbody>
<tr>
<td>● <strong>Interoception and Introspection</strong>: Elucidate the mind-body connection as it pertains to stress response and impact on the patient’s illness management through practicing the skills of interoception and introspection</td>
</tr>
<tr>
<td>● <strong>Identify and Access Unconscious Processes</strong>: Help patient to identify and access unconscious processes such as the connection between emotions and psychogenic cues.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step Two: Language Development</th>
</tr>
</thead>
<tbody>
<tr>
<td>● <strong>Burden Identification</strong>: Assist patient in identification of burdens (actual or perceived) created by illness meanings which keep patients from getting their needs met in adaptive ways.</td>
</tr>
<tr>
<td>● <strong>Voice Recognition</strong>: Promote patients ability to recognize their voice and how it can be used as a more effective way of getting their needs met.</td>
</tr>
<tr>
<td>● <strong>Practice using voice</strong> within the peer group which includes accepting feedback and moving into more active roles within the group.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step Three: Congruence</th>
</tr>
</thead>
<tbody>
<tr>
<td>● <strong>Developing Congruence in All Domains</strong>: Assisting the patient in developing congruence in social, academic, and family domains in order to fulfill his/her needs in new and adaptive ways.</td>
</tr>
<tr>
<td>● <strong>Continued Connection of Emotions with Psychogenic Responses</strong></td>
</tr>
<tr>
<td>● <strong>Separate Psychosomatic Issues</strong> (exaggerated pain) from somatic symptoms (pain)</td>
</tr>
</tbody>
</table>
### Step Four: Patient Meaning Response Testing
- **Testing Meaning Responses** and observing subsequent healthy changes
- **Psychogenic Regression Process** (increase in psychosomatic complaints) as illness meanings are challenged and accompanying benefits are given up
- **Process Buy-In:** Encouraging patient process buy-in regarding how they previously attempted to meet their needs through maladaptive behaviors

### Step Five: Systemic Adjustment
- **Family Identification and Movement Away from Needs-directed Behavior (power)** towards the use of adaptive behavior and voice.
- **Therapist-family Collaboration:** Work together to explore new, adaptive ways to support the patient’s healing process.
- **Parent Support:** Provide parental support and validation.
- **Identify Guilt and Shame Process** in parenting a child with complex medical needs

### Phase III: Meaning and Expression

#### Step One: Creating Changes in Meaning
- **Meaning Responses and Change:** Using the patient’s meaning responses to gauge where illness meaning has changed and need for further intervention.
- **Continued Language Development:** Continuing to help the patient develop language and generalize the use of voice towards more strength-based language (i.e. survivor vs. victim.)
- **Testing Response Integration:** Testing the patient’s integration of illness meaning change and healthy needs-directed behaviors.
- **Physiological Response Changes:** Paying attention to changes in the patient's physiological response changes when exposed to previously addressed illness meanings.

#### Step Two: Systemic Acceptance of Change
- **Predict and Prepare** the family for upcoming success and challenges.
- **Test the family for systemic changes** in illness meanings, as well as for the elimination of negative coauthorization processes.
- **Systemic Buy-In and Integration:** Establish buy-in and integration from entire family
- **Reorienting Parent Identity:** Help parents to reorient their identity to include meanings outside of being the “parent of a sick child.”

### Phase IV: CHANGE generalization and reintegration

#### Step One: Change beyond the individual and system
- **Set-Up Challenge Responses:** Help the patient and family anticipate common challenges
- **Adjustment and Reintegration into Healthy Development:** Provide appropriate referrals for ongoing care and prevent any attempt to regress in order to stay in treatment.

#### Step Two: Graduation
- **Group Reflection:** Provide opportunities for patients and family members to reflect on their growth and success throughout MEND
PHASE I – ORIENTATION, ASSESSMENT, AND LANGUAGE

Step One: Orientation and Development of Therapeutic Relationship

Step Two: Biopsychosocial Assessment

Step Three: Language Learning and Teaching

The first phase of MEND begins with a process of orienting the family to the program and engaging the family in treatment. In the first session the therapist familiarizes the child and the family to the rules and expectations of the program as well as the therapeutic format including the peer relationships that guide the treatment. While much of the work is geared toward orientating patients and families to the program, the primary goal in this process is building relationships and trust between child, family, therapist, and peers in order to gain patients and family members’ buy-in to the possibility of change. The relationships built during this time will become the fulcrum for change throughout the program.

Once a therapist assists the child and family in developing a sense of trust and expectancy for change, the therapist will begin assessing the family system at multiple ecological levels. As a therapist progresses through an assessment process with the
family, he is also charged with learning the language and meaning given to the illness by each family member and their subsequent psychogenic responses. Common psychogenic responses are changes found within the autonomic nervous system, such as changes in respiration, skin color, eye contact, posture, and speech (volume, cadence, and air pressure behind voice). Psychogenic response will be covered in more detail below. This process of learning the language and meaning is not only an assessment process, but also an important way to elicit a connection and shared understanding between the therapist and the family system that is necessary before the therapist can attempt to elicit changes in the family coping patterns.

Step One: Orientation and Development of Therapeutic Relationship

Orienting the patient and family to the MEND program begins during the initial patient assessment or intake, and includes familiarizing the patient and family members to the program guidelines, goals, the peer-driven model, and the therapeutic environment. During this orientation phase, the therapist takes a strong, supportive stance of the patient and family members. A foundation of trust is built and strengthened allowing patients and family members to rely heavily on the therapist that will later allow the therapist to challenge patient and family member coping patterns.
Goals of Step One

1. Development of Therapeutic Relationship: Developing a safe and supportive therapeutic alliance with both the patient and his or her family.
2. Patient and Family Buy-In: Soliciting initial programmatic buy-in including acceptance of the programmatic rules and expectations and therapeutic process.
3. Integrating Patient into Peer Group: Integrating the patient into the peer environment and establishing appropriate peer positions between the patient and those peers who struggle with similar processes.

Development of Therapeutic Relationship

During this orientation phase the patient will rely heavily on their relationship with the therapist. As such, the supportive stance of the therapist during this period strengthens the therapeutic relationship and builds a foundation of trust that will be further built upon. Throughout the course of treatment, the therapist will use certain interventions with the patient and family to create leverage needed to influence second order change. These changes would not be possible without trust and acceptance between the therapist and patient, and the therapist and family members. It is imperative to note that if the patient or their family
does not buy into the therapeutic relationship, then moving forward with any interventions, other than those designed to build the relationship, would be ineffective.

**Patient and Family Buy-In**

The acceptance of the possibility of change (also known as buy-in) is a complex but critical process that occurs in three distinct areas over the course of treatment -- programmatic buy-in, process buy-in, and systemic buy-in. Programmatic buy-in occurs primarily over the course of the first phase of treatment and refers to the patient’s acceptance of the program model. Process buy-in generally occurs during the patient’s third phase in treatment and refers to the patient’s internalization of the MEND model of language, meaning and needs-directed behavior. The final area, systemic buy-in, occurs during the last phase of treatment and refers to the family’s acceptance of the MEND model. While process and systemic buy-in (described in greater detail in Phases 3 and 4, respectively) are important in creating second-order change, neither can occur without first establishing programmatic buy-in.

The process of creating programmatic buy-in begins at intake, as the patient and family are introduced to the MEND program. The patient and family are informed of the programmatic rules, which consist of dress code, attendance, and overall conduct. They are invited to participate in the program with an open willingness, and reluctant
patients are often encouraged to try the program out for three days before determining whether or not MEND is right for them. This “trial offer” tends not only to decrease the patient’s initial stress response to a 21-day intensive therapeutic program, but also helps to establish early patient buy-in. Programmatic buy-in is observed and assessed through patient participation between the patient and therapist and the patient and peers. In addition, observation of the patient’s stress responses to program elements, such as rules, language, or activities, can be used to determine buy-in.

**Integrating Patient into Peer Group**

Setting and maintaining a positive peer culture is the responsibility of the MEND therapist. A positive peer culture is one whose members are a connected and united, moving towards health, and holding members accountable with respect and without judgment. The therapist will use this positive peer culture to leverage challenges, motivate patients, actuate normalization processes, and emphasize accurate responses. While some patients are quick to engage with peers, a patient’s struggle or standoffishness with peers is not taken as an indicator of resistance to the buy-in process. Instead, the patient might be struggling with some social awkwardness due to their illness and may actually be putting in significant effort into fitting in with their peers. Many children with chronic illnesses have spent much of their childhood with adults and have very few opportunities to help
normalize their experiences among their peers. While these children often present as socially well-adjusted with an above average vocabulary and relative ease interacting with adults, when placed in an unfamiliar peer group, children may experience it as challenging and stressful. While the patient just entering the MEND program may not be used to interacting with peers and find it uncomfortable or even stressful, the therapist is there to help them adjust to the new environment. For example, the therapist can introduce the new patient to the peer culture in stages, or align the new patient with a supportive senior member of the group to help ease any anxious feelings. Thus these struggles show a willingness to engage and can be seen as a sign of the patient beginning to buy into the initial phase of treatment.

The purpose of the group peer model is to help align a new patient with others who are experiencing similar processes. By participating in a peer group, patients are exposed to others in similar situations which helps the patient normalize and better understand their own experiences and moves the patient towards programmatic buy-in. Because the group is open and members are at various stages of treatment, peers help move the patient along into advanced treatment stages through mentoring and role modeling. Since social acceptance is driven by a developmental need for socialization, peer influence can be used as a significant leverage point within the patient’s process. Often these alliances and peer relationships form naturally through normal social processes and can have either a positive or negative
influence on the patient’s treatment. On the positive side, a patient has made a friend, a normal healthy process of socialization. This relational aspect can have a significant influence on the individual patient and their therapeutic process. Assistance from the patient’s peers can be solicited and managed by the therapist, especially since the therapist has already established an individual relationship with each patient and can identify which peers may be a beneficial influence in a particular patient’s process. The negative alternative is that the patient is drawn to a peer whose avoidance or disengagement is more aligned with his or her own behaviors. Such a relationship can normalize and validate the avoidant processes or provide a hiding place for the patient. Therefore, the MEND therapist may need to break these maladaptive alliances early on to provide an environment where both patients can then move forward with their own processes.

Peer Positions

Throughout treatment, the patient generally fits into one of three categories within the peer group. The first is the patient who has yet to begin the process of change, and who has learned of the future therapeutic process from their therapist and peers. This patient is often fearful of the change process and believes that supporting other peers who are resistant to change will help them avoid their own process. Second, there are the patients who are considered the “power brokers” in MEND. These are patients who have accepted and
benefitted from the process themselves and provide experience, strength, and hope to the others. The MEND therapist can often use such power brokers to move patients in common directions, strengthening their bonds with peers, and staging healthy parallel movement. This, again, is a process of social acceptance; if the most influential member in the group (i.e. the power broker) moves towards more healthy processes, other members in the group will want to mimic or parallel such therapeutic progress in order to maintain acceptance by the group. Lastly, are the patients who are in the position of being ready to change. These patients showed effort in gaining social acceptance from their peers, especially the power brokers, and are highly motivated to change. Often this desire to change is strongly influence by desiring a common experience with the senior members or power brokers of the group who have already made changes.

Throughout this process the MEND therapist solicits strong positive reactions from the peer group whenever an individual patient moves in a healthy direction. This cheerleading by their peers is a powerful directional tool, showing patients that their social needs can be met in positive ways by their peers. This overarching peer process becomes the social directive of the group and helps move all participants’ in a single direction towards positive change.
Step Two: Biopsychosocial Assessment

Biopsychosocial assessment is primarily an observational process of information gathering from the medical, family, social, and academic domains. Generally speaking, the overall goal of the MEND therapist during this step is to evaluate the patient and his or her systems (family, social, and academic) in relation to illness meaning and sources of stress.

Goals of Step Two

- **Identification of Illness Meaning and Coauthored Stories:** The perceived meaning(s) of the patient’s illness (or illness meaning(s)), as well as how those meanings are coauthored by the patient’s systems (family, social and academic.)

- **Identification of Stress Responses:** Those stress responses present in the patient resulting from a coauthored illness meaning (e.g. “My illness makes me unlovable.”)

- **Assessment of Patient Development:** Areas of developmental delay (both socially and psychologically) resulting from the child’s illness or illness meaning.

- **Assessment of Systemic Functioning of the Family:** How the patient’s family functions as a system, as well as its contribution and response to coauthored meanings of illness.
• **Identification of Needs Directed Behavior (Power):** The patient’s use of maladaptive needs-directed behavior (or power.)

**Illness Meaning and Coauthored Stories**

Children rely on their familial and social environment to create meanings for events in their lives. These meanings promote and govern children’s behaviors in an attempt to create congruence between their internal experience and external expression. For example, a toddler who bumps into a table will look at his parent to determine whether or not the minor pain is something to be upset about. If the toddler’s parent appears worried or angry, the toddler may perceive this internal stimulus as unpleasant or dangerous, and will begin to cry. The same process is at play for pediatric patients as they look to their parents to help them understand the meaning of their illness. MEND therapists have witnessed the most common meanings developed and experienced by the chronically ill patient as:

- Different
- Limited
- Broken
- Unacceptable
- Maladaptive power
- Burden
- Responsible
- Shameful
- Guilty
- Illness over identification

To maintain congruence between the inner experience and outer expression, a child will solicit
other individuals or systems to reinforce or coauthor these meanings. However, the coauthoring process can also enhance negative meanings which adds to individual and systemic stressors and promotes maladaptive behaviors that further reinforce these meanings. A family struggling with a child’s chronic illness can feel pulled in different directions by the responsibilities and medical regimes associated with the illness. The main focus of the MEND program is influencing second order change that includes changing meanings and behaviors within the entire family system in regards to the illness. At this stage of treatment, the MEND therapist seeks to identify patterns of coauthorization in the family, social and academic domains.

One way that the MEND therapist assesses meaning is through the use of Socratic questioning and experiential activities such as play and art. Through these activities, the therapist listens for the family’s understanding of the meaning and impact of the illness on their individual lives and their overall family structure. Activities include identifying patterns and meanings that have been learned generationally. The goal is to identify how a family’s sense of meaning and overall development is influenced by generational patterns of influence. These influences contribute to coauthorization of meaning experienced by each member in the family.

An example of how coauthorization of meanings occurs through generational influence is the child whose family has placed a high value on education which can be traced through previous generations.
If the child feels uncertain about her academic ability, she may subconsciously put little effort into her studies. When confronted with poor academic performance, the child’s lack of effort provides an excuse as well as a reason by which the child can explain the outcome. The outcome both affirms the child’s worries about her lack of ability and provides an excuse that if she had only put forth her best effort, she would have done well. If she receives a good grade, then all is well and she has escaped the outcome of her uncertain abilities. If she receives a poor grade, then she can preserve her sense of self by explaining that she could have done well if she had studied more. This preservation of self creates a double bind that is based upon a child’s negative self-perception of her abilities and can keep a child locked into her belief of lacking academic abilities and refraining from putting forth her best efforts. Family, social, and academic spheres of influence can contribute to this pattern by enforcing these beliefs through typical messages, including: “If only you had tried harder” or “I know math is hard for you.”

Similar double binds can be found in families with a chronically ill child. The patient’s ability to get her needs met (i.e. preserving a sense of self) can occur through influencing or at times manipulating her family’s response to her illness. For instance, if a child who has diabetes is not experiencing adequate control over her condition, the same pattern of not believing in her abilities related to her illness can result in efforts that prevent her from putting forth her best efforts in an
attempt to preserve her sense of self. Family members assist in coauthoring these meanings through statements such as: “I know it’s hard for you to manage your diabetes” or “You’re too weak to manage your diabetes” and through actions which place the majority of the responsibility for managing the disease on the parent rather than the patient. The following are examples of coauthoring patterns found in the family, social, and academic domains.

**Family**

- **Fearful Energy:** The overt and covert overprotective behavior generated by the hyper-vigilant family system. “Be careful not to be too rough when playing with your brother, you know it’s not good for him to get too excited.”

- **Cushioning:** The process of minimizing or softening imputes from the family system in an attempt to protect the ill child from heavy or burdensome information. This can cause more of a disconnect as the system and the child don’t share accurate information. “Your grandfather is sick and won’t be able to visit for a little while but he will make a full recovery and be fine soon.”

- **Excusing:** Placing blame on the illness for unmet expectations. “It’s not your fault, you could have passed that class if you were healthy enough to attend regularly.”

- **Expectation Incongruence:** Holding different expectations for the chronically ill child and their healthier siblings and peers. “We expect..."
“your grades to be better, you know your brother has limitations that you don’t.”

- Over burdening: Placing responsibility on the chronically ill child for systemic stressors and burdens. “It costs too much and we just can’t afford it right now; your mom is not working because of all of the doctors’ appointments, and your medications are very expensive.”

- Unbalancing: Unequal attention and energy provisions between healthy and ill children within the family system. “How come mom never comes to watch my games? She spends all her time with Jonnie and forgets about me.”

- Constriction: The systemic influence of limiting potential growth. “Maybe next year, I don’t think you’re up to it quite yet.”

Social

- Limiting: Allowing limited access to peer participation due to activities believed to be outside the range of the chronically ill. “You cannot go with them because they are going to be doing things you are unable to do.”

- Avoidant: Being avoided by peers and social groups due to fear and misunderstanding of the illness. “You can’t play with us because you’re sick.”

- Comparing: The comparing of the healthy and the chronically ill. “I’m not like them; I’m can’t do what they do.”

- Isolating: The ill child isolating from peers and social opportunities. “I don’t fit with others so I will be by myself.”
• Creating: The creation of a social network that excludes activities and peers which are active in activities believed to be outside the patient’s abilities. “Me and my friends like to stay at home and play video games, we don’t really like to play outside”

• Adopting: Adopting the negative imputes from society about the chronically ill as true. “I don’t really think college and marriage will ever be for me.”

**Academic**

• Displacing: Placing a chronically ill child in special education classes. “In this classroom setting you will get the special attention that you need.”

• Accommodating: Making accommodations for a chronically ill’s needs or limitations. “Jonnie, remember you need to leave class five minutes early and go to the nurse’s station to have your blood sugar taken before lunch.”

• Expectation: Lowering academic expectations for the chronically ill. “You don’t have to complete the entire assignment, just do your best.”

• Exclusion: Excluding the chronically ill child from regular social, academic and athletic activities. “You can come and sit with me while the other kids go to PE and recess.”

• Acceptance: Accepting the child into the general academic population. “You can attend just like everybody else.”

These common illness coauthorization processes between child and family result in the child having a
significant amount of influence, or power, in the family system. Often when children have this much influence in a family system, it can be a stressful experience for them. This subsequent stress response to these family patterns and meanings will become the focus of treatment in the next phase of MEND.

**Stress Responses**

Understanding the biological processes and the negative effects they can have on health is an important element of the biopsychosocial aspect of the MEND model. The primary mind-body connection focused on in MEND treatment is the connection between psychological processes and the Sympathetic Nervous System (SNS). The SNS is the system which triggers the biochemical and physiological changes brought about by a fight, flight, or freeze response. The stress hormones produced during these responses can impact patients in ways that exacerbate their illness, such as: deregulation of hormonal and immune systems, susceptibility to infection, chronic fatigue, and depression. Prolonged secretion of the stress hormone, cortisol, can negatively influence a patient’s illness and self-management due to the following effects: impaired cognitive performance, suppressed thyroid function, blood sugar imbalances such as hyperglycemia, higher blood pressure, lowered immunity, increased inflammatory responses, and slowed wound healing. For example, the suppression of a patient’s cognitive function
(caused by chronic SNS activation) can inhibit their ability to process emotions, which in turn could lead to depression, anxiety and ultimately, contribute to medical noncompliance. In addition, the introduction of stress hormones can further compromise the patient’s immune system which can further tax and exacerbate a patient’s health.

While the SNS has both short-term and long-term physiological flight, flight or freeze responses, our perception of the triggering event (i.e., meaning) decides the type and amount of stress hormones that are secreted when the SNS is activated for more than a few seconds. Actuation of the negative illness meanings explored during this phase of treatment is frequently the underlying cause of chronic SNS activation in children with chronic illnesses. That is to say, meanings associated with illness, such as “I’m going to die”, “I’m responsible for my family’s problems”, “I’m broken” and “I’m not normal like other children”, are often interpreted in the body as a physiological threat to the patient’s wellbeing. The end result is the physical and psychological impairment of the chronically-ill child by a process which is often unconscious, but becomes conscious throughout treatment.

The pediatric patient who is living with a chronic illness exists in an environment full of real or perceived threats, causing the amygdala to actively engage the threat response system. The Sympathetic Nervous System (SNS) is the system that triggers the biochemical and physiological changes brought about by a fight/flight response.
fight/flight response is triggered over 1,400 different physiological and biochemical changes occur in the body. But there are also psychological effects making us more alert, aggressive, angry, fearful etc., which all motivate us when we are physically threatened. Whenever we perceive we are physically or psychologically threatened our brain triggers the release of electrical impulses and a variety of hormones. There is a complex hormonal cascade of over 30 stress hormones, such as adrenaline, noradrenaline and cortisol, which have a powerful and widespread effect on our body's biochemistry, physiology and psychology. These fight/flight response is affected by our perception of the event, which decides the type and amount of stress hormones that are secreted. Research has shown that chronic activation of the fight/flight response can be a factor in causing a number of psychological and physiological health problems.

If these stress responses could be treated in real time, the benefits to the chronically ill child’s quality of life and longevity could be profound. Using the MEND treatment model, the therapist helps the patient access information and make healthy compliance decisions, learning how to integrate information when the body can best process it. When the child is able to process and integrate the information during times of low stress they are better able to draw upon those skills during times of stress or crisis.
MEND: Mastering Each New Direction

Circular processes of system feedback toward meaning establishment or management

- Meaning
- Stressor
- Fear/Anxiety
- SNS Deregulation
- Decreased Cognition
- Decreased Integration
- Maladaptive Stimulus Response
- Poor Compliance
- Coauthored Contextual Meaning
The MEND treatment focus is to empower the child with the tools they to decrease these stress responses, thereby increasing their cognitive and integrative abilities. Once the chronically ill child learns how to master these responses, other issues, such as medical compliance and social functioning, can be addressed. Some of the stresses associated with chronic illness take a heavy toll on the entire family: financial, social, and emotional. Developmentally, children often interpret this systemic stress as being “their fault” and internalize the stressors. To help ease the child’s feelings of guilt and responsibility, it is important to include members of the patient’s family to help realign the child and family member(s) perception of the illness. As the patient proceeds with their developmental tasks in treatment, the illness can continue to cause additional stressors (such as returning to school or social acceptance; limitations on physical abilities and concerns about quality of life) and it is important that family members are able to continue to address these stressors after treatment is complete.

Development

Children who experience stressors individually (physical illness) and systemically (family stressors) are at risk of delayed or arrested developmental processes, including physical, cognitive, and social processes. Because of this, it is important for the MEND therapist to determine a patient’s level of development along the spectrum of normal child
development in these areas. Special attention is given to a child’s social development as opportunities to develop healthy social skills may be limited by an inability to attend school. Similarly, patients with illness meanings that include being “broken” or “unworthy” may develop a maladaptive avoidance of social situations. The MEND therapist develops a treatment plan to address development processes. Attending to development is important in reducing actual or potential stressors the patient may experience due to not being prepared to socialize or function at an age-appropriate level. In addition, interventions must be designed to fit the patient’s unique level of development in order to facilitate the process of change.

Systemic Functioning of the Family

In addition to delays in developmental, family functioning may also impact a patient’s ability to cope with illness. The MEND therapist must accurately assess overall family functioning, issues of power (explained below), and how the family responds to stress in order to determine if a family is capable of managing the changes that will be implemented throughout the program. Once the MEND therapist identifies a child’s illness meanings and methods of coauthorization, the next step is determining the child’s stress responses to these meanings. In the MEND model, the concept of stress or a stress response, centers on the effects of the sympathetic nervous system (SNS) on
cognition, information integration and memory. Each of these factors can be measured, tested, and observed in real time within the MEND treatment process. The therapist focuses on reading the child’s SNS responses through attention to psychogenic expression such as increased respiration, blushing, and foot tapping. In addition to external cues, the patient may also experience SNS responses which may not be readily apparent but are of equal importance such as internal bodily responses of immunosuppression, pro-inflammatory processes, and the disruption of regeneration processes (specifically, sleep and digestion) as well as the patient’s cognitive ability to understand and remember their often complex treatment regimen. Both the internal and external expression of SNS involvement are important, since the MEND model argues that the comorbidity of these factors are responsible for negatively influencing issues of medication adherence, quality of life, and longevity. In other words, as internal physical and external family system stressors are placed upon the patient, the patient’s ability to experience normal healing processes is suppressed.

Identification of maladaptive needs directed behavior (power)

The pediatric patient who has a history of a chronic illness learns early on that the illness, and accompanying medical regimen, holds significant emotional energy within their family, social, and academic settings. Children learn about their ability
to produce this emotional energy and utilize it to get their needs met (e.g. saying that she is in more pain than is accurate in order to get attention). This needs-directed behavior is learned within the process of the illness and is a powerful force in the family. This use of power by the child should not be seen as a character defect or bad behavior, but the natural result of growing up with a chronic illness. For example, a child whose illness meaning includes being “broken” may purposefully appear unable to comply with her medication regimen in order to elicit support and/or attention from the family system. Parents, who already feel guilty for having a sick child, may respond by providing attention in an unhelpful manner (e.g. by lecturing the child on the importance of medication compliance.) However, these types of responses only reinforce the child’s maladaptive meaning (i.e. “Because I am unable to manage my medications, I really must be ‘broken’”). If this maladaptive process is allowed to continue, it will impact the child’s development, promote the avoidance of healthy medical and emotional growth, and have negative effects on physical health (via the SNS.) It is the responsibility of the MEND therapist to carefully observe and identify how the patient uses his/her power to get their needs met in order to later make the adjustments necessary for the patient to get their needs met through appropriate, developmentally healthy ways (e.g. having the patient verbally communicate her need for attention).
Step Three: Language Learning and Teaching

The most crucial and difficult process within the MEND model is that of language learning. While gaze behavior and emotional reciprocity are how meaning is transmitted, language is how meaning is expressed. Language can take the form of tactile, written, or verbal expression, and may be congruent or incongruent with the patient’s emotional experience. More importantly, language is an observable process that changes as the patient’s meaning changes. Language – in all of its forms -- plays a key role in the therapist’s ability to track and nurture changes in illness meanings over the course of treatment. While learning the patient’s language is a critical process, it is important to note that within the context of treatment language learning is reciprocal: as the therapist learns the patient’s language, the patient is also learning the languages of the MEND therapist and the group.

Goals of Step Three

- **Language Learning** To learn how a patient best expresses psychogenic congruence (i.e. through tactile vs. verbal expression).
- **Normalization of experience**: Using the peer process to normalize the illness
experience of the patient and his or her system.

- **Language Teaching and Shaping:** Shaping the patient’s language by placing emotional and attentional energy into those areas of psychogenic congruence, and by purposely refusing to place similar energy into those areas of psychogenic incongruence. In addition, providing psychoeducation to patients and family members in order to create a common language that can be used to talk about the illness experience.

**Language Learning**

Learning the language of a chronically ill child or adolescent is essential to effective treatment. Each child has their own language that the therapist must learn and master before and during treatment to address the underlying issues that affect the child’s health. Learning a child’s language not only involves verbal communication but also understanding their psychogenic responses to emotionally driven content and the behaviors they use to get their needs met. For example, when a child is chronically ill, their illness takes on meaning because the illness has become part of their identity. Therefore, when a child speaks about herself in relation to her illness, she may feel that her illness means she is “broken,” and these feelings are shown by her psychogenic responses. Although her age and level of brain development may make it difficult for her to articulate these feelings, their
psychogenic responses (i.e., looking uncomfortable, lack of eye contact, flushing, change in breathing, etc.) are another form of communication for the therapist. Another component of the child’s unique language – behavior – shows the therapist how the child gets her needs met. For example, a child may cry or throw a temper tantrum to get what she needs at that time: attention, affection, emotional responses, etc. Since the child has successfully used these behaviors to get her needs met in the past, she will most likely continue to do so. Lastly, the final component of each child’s specific language is her actual language – the words she uses to express her needs. However clearly she seems to be communicating verbally, it is important for the therapist to see that a child’s verbal language is not always accurate to their experience or effective in meeting their underlying needs. Therefore, it is essential that the therapist observe and master all aspects of the child’s language -- psychogenic responses, behaviors, and verbal style – in order to treat them effectively.

In addition to becoming an expert in their patient’s individual language, understanding the family’s verbal language, behaviors, and psychogenic responses to the child’s illness will also help the therapist provide the family with the skills and tools they need to function in the child’s best interest. For example, to gain insight into how the child’s illness is viewed and managed within the family, the therapist should take note of how the parents describe the child’s illness both to the therapist and to the child. Many families will treat a
chronically ill child differently than they would a healthy child, in the process giving the child the feeling that he is “different” or “broken.” Furthermore, the family system may also have their own psychogenic responses to the child’s illness, such as developing medical issues themselves, avoiding the child, or becoming emotional, angry, or frustrated with the child which often produces feelings of guilt or shame in the process. Becoming familiar with how the family defines, treats, and experiences the chronically ill child will further enable the therapist to treat the whole family – and the child’s experience of their family.

Psychogenic Congruence

Part of the process of learning a patient’s language is paying careful attention to cues of psychogenic congruence between a patient’s expressed emotional responses versus their observed physiological response to their internal emotional processes. Simply put, when a patient experiences an emotion his body’s physiological processes are always congruent with that emotion. For example, feelings of anxiety are always accompanied by increased heart rate and respiration, even if those changes are not visible to the casual observer. Psychogenic congruence, therefore, is the agreement between a patient’s outward expression of emotion, her internal emotional process, and her physiological response. For patients, psychogenic congruence is often referred to as the process by which our “insides” match our “outsides.”
It is the therapist’s ability to read emotional and psychogenic cues that creates the greatest impact with the chronically ill patient. Through the process of language learning, the MEND therapist observes how the patient’s body responds to meaning. Psychogenic responses to emotion can be observed in multiple ways: changes in respiration, skin color, eye contact, foot bouncing, speech changes (forced, quiet, scattered), crossed arms, or any other changes in baseline behavior. The MEND therapist begins to learn his patient’s baseline psychogenic expression on the first day of treatment. For example, if a patient states that he or she is responsible for “overburdening the family” as a result of his or her illness, the MEND therapist would expect to see the psychogenic markers (e.g. flushed complexion and lowered gaze) congruent with the implied feelings of shame. While each patient’s psychogenic response to a particular meaning or emotion is different, it is impossible for the patient to congruently experience these meanings or emotions without the associated psychogenic responses.

Expressive Activities

In order to learn how a patient best expresses congruent language, whether it is through tactile or verbal expression, MEND therapists engage in various expressive exercises. Throughout the program, the therapist will assign a number of expressive exercises across multiple domains and modalities. While the specific order and domains of assignments should be reflect the patient’s
developmental strengths and challenges, the therapist should assign at least one tactile, written, and verbal assignment before determining how the patient expresses themselves in the most congruent way. Once the MEND therapist is able to distinguish how patient’s best express congruent meaning and emotional responses, he or she will use this information when choosing assignments to process in peer or multi-family group which will work towards changing the patient’s illness meanings.

*Art:* Art is an expressive tool used by the MEND therapist to learn and confirm the components of a patient’s illness meaning. The colors, images and stories depicted in a patient’s art can be important tools to help the therapist understand his experience. Therefore, it is not only the product of the art session, but the patient’s affect during the exercise that provides valuable information.

*Writing:* Writing is another form of expression that can be a useful tool for the MEND therapist seeking to learn a patient’s language or understand their congruence process. Journaling is an activity used each treatment day to set the tone or topic, and may prove to be the patient’s most accurate form of expression. Early in the treatment process, while many MEND patients are still adjusting to the peer culture, writing processes between therapist and patient only can feel more private and less invasive, and help with relationship building. As treatment progresses, the written information in
journal conversations and the information written for processing with the group should become more congruent. This is a sign that the patient is comfortable and trusting of their therapist and the group.

*Verbal:* For obvious reasons, one-to-one verbal communication is often a more reliable way to assess a patient’s congruence than art or writing exercises. No matter how honest and insightful the drawing or journal entry, nothing will replace the experience of a therapist compassionately, empathetically listening and talking with a patient.

*Psychogenic Congruence throughout Treatment*

Psychogenic congruence is used throughout each phase in MEND to help facilitate long-lasting change for patient and family members. In each phase of MEND, the therapist will observe and assess for signals of psychogenic congruence (such as breathing, skin color changes, respiration) for distinct purposes depending on the phase of treatment. In Phase I psychogenic congruence is used to assess a child's baseline behaviors and pinpoint areas of stress or incongruence. In Phase II, psychogenic congruence is used as a point of intervention where therapists will address areas in which incongruence is noted. In Phase III, psychogenic congruence is used to assess whether changes in illness meanings have occurred and clarify where additional intervention may be needed. In Phase IV, psychogenic congruence is used to concretize changes and reveals to the therapist and
patient that long-standing change has indeed occurred.

Normalization of Experience

As noted above, many children and families assign meanings to chronic illnesses that are maladaptive. This process is only amplified by the current medical system, which tends to provide very few resources to help normalize the experiences of children or families with chronic illness. As such, one of the primary goals of Phase 1 is to begin the process of meaning normalization. To promote meaning normalization, the MEND therapist will utilize art, written and verbal expression as well as peer positioning to place the patient into contact with information about their own experiences and how they are similar to the experience of others. For example, when patients are placed together with those who have similar diagnoses or medical experiences, one of their primary illness meanings is challenged: “I’m sick therefore I’m different from everyone else.” Another example of how the peer model can be used in the meaning normalization process, would be to assign the patient to write about what another patient with their shared illness might experience (e.g., “If you walked a mile in my shoes you would know what it’s like to (fill in the blank.”), and then have them share this writing with peers and process common experiences.
Language Teaching and Shaping

The MEND therapist works to learn the language of both patient and family members as well as teaching and shaping a new language that will help facilitate discussion of the illness and its impacts. To assist in creating this language, psychoeducation is used to provide an overview of how the nervous system processes information, the physiological aspects of emotion, stress response of individuals, and overall cognition and child developmental processes. Educating on these areas helps to create a common language in which the therapist, patient, and family system can begin to discuss the effects of maladaptive illness meanings and how family patterns and individual responses may be coauthoring such meanings. This process helps to shape the patient’s use of language to include only those language processes which are accurate, healthy, and developmentally appropriate.

Zero Response

As another way to help shape language, MEND therapists engage in the conscious placement of intentional energy in order to influence how patients express themselves. Through placing emotional and intentional energy into expressions of psychogenic congruence (e.g. smiling when talking about something positive) and by purposely refusing to place energy into expressions
of psychogenic incongruence (e.g. smiling when talking about a difficult situation). An example of this would be the therapist placing no response energy into processes which are maladaptive and attached to a negative meaning. So when the patient tries to use the illness or treatment side effect as an excuse to avoid or minimize a responsibility, the MEND therapist’s affect remains flat and places no response energy into this process. The therapist may offer help to the patient in this area or redirect attention to another patient who is actively engaged in adaptive processes and then later return attention and solicit participation from the initial patient. If the patient accepts this help and then moves forward, the therapist will provide positive energy in response to this challenge.

**Phase I Milestones:**

By the end of Phase I, the MEND therapist should be able to accurately identify a patient’s specific illness meanings, including how these meanings are coauthored by the patient and his or her systems, and how the patient uses maladaptive power (or needs-directed behavior) in order to meet his or her developmental and emotional needs. In addition, the therapist should understand the patient’s most common stress responses and psychogenic cues as well as patient and family development and level of functioning overall. The therapist should be able to clearly identify how a patient most easily expresses congruent language and those areas which require therapeutic intervention in order to elicit congruent
language. Understanding how family members respond to the patient’s congruent and incongruent language is also needed. At this point, patients should be able to accurately express and process common illness experiences with the therapist and peers, and, with guidance, begin to become more open and aware of the emotional content attached to these experiences.
PHASE II – INTROSPECTION AND CONGRUENCE

Step One: Mind-body Connections
Step Two: Language Development
Step Three: Congruence
Step Four: Patient Meaning Response Testing
Step Five: Systemic Adjustment

The goal of Phase Two is to encourage an understanding of stress response patterns within the child and family and to begin to generate psychogenic congruence. It is during phase two that the patient will begin learning how they emotionally and physically respond to the unconscious meanings they have created about their illness, and to identify the burdens these meanings carry. As the patient transitions from Phase One to Phase Two, they will be expected to take a more active role in treatment. In particular, the patient will begin the process of looking inward to learn how their emotional processes impact their physical well-being.

Much of the work in this phase is informative and focused on helping the patient identify stress response patterns within themselves and their family system. As the patient identifies these patterns, the therapist will probe for disconnects in
congruence and encourage the child to modify their language so that their emotional, verbal, and psychological responses to stress match their physiological responses resulting in psychogenic congruence. In addition, interventions are focused on helping to facilitate conversations within the family that will help them respond positively to the child’s new, direct ways of asking for needs to be met.

Towards the end of Phase Two, the therapist will start the process of testing meaning changes to ensure that the patient has fully integrated the lessons and voice gained in treatment. Regression processes, resulting from incomplete integration, are managed here as patients struggle to let go of the secondary gains which originally drove their illness meanings. A key sign that the child is ready for the next phase of MEND is that she experiences accurate and consistent congruence and begins to adopt new meanings to both her illness and the stress she experiences.

**Step One: Mind-body Connections**

During this step, patients and family members learn about the mind-body connection as it relates to the stress response system of the body and the subsequent impact on the patient’s illness management. The acquisition of this mind-body connection enables patients to learn how their emotional and thought processes contribute to their physical health.
Goals of Step One:

- **Interoception and Introspection:** Begin practicing the skills of interoception (paying attention to the physical cues of the body, such as pain, tenseness or changes in respiration) and introspection (paying attention to one’s mental and emotional state).

- **Identify and Access Unconscious Processes:** Begin noticing the connection between accurate, congruent emotions and their associated psychogenic cues.

**Interoception and Introspection**

Often the MEND patient will have significant disconnects from a body they may feel has failed them. To highlight relevant mind-body connections, patients learn and begin practicing the skill of interoception, paying attention and attending to the body’s physiological responses, such as pain, tenseness or changes in respiration, and introspection, paying attention to and reflecting on the body’s emotional and psychological responses. The difference between interoception and introspection is the emotional state. Introspection deals with the mental and emotional state while interoception deals with the physical state. When these two processes are connected and working together it is called congruence. As patients notice the connections between accurate, congruent emotions and their associated psychogenic cues, they bring their unconscious processes into consciousness. Conscious awareness of these
connections helps facilitate self-management of their illness.

The process of teaching the MEND patient to attend to the internal responses of their bodies begins with grounding. Grounding is a mindfulness concept that refers to the process by which the patient uses common physical stimuli (such as breathing) in order to turn his or her attention towards internal physiological processes. The grounding process begins in a place where there are little to no environmental distractions. The MEND therapist prompts the patient to sit with their feet on the floor and their backs supported by the chair. Then the therapist will ask the patient to just feel where their body comes in contact with the chair, to notice their weight and process of breathing. Once the patient is in the moment and grounded, true interoceptive and introspective work can begin. The therapist will begin by asking the patient to report on anything they notice they are feeling or thinking. The therapist will prompt the patient to notice as things float in and out of their mind, but will remind the patient not to stop and process any of these thoughts or feelings. Then, the therapist will introduce aspects of the patient’s experience with illness meaning and ask them to notice how their body responds. As the patient reports on their body’s experience, the therapist can process the meanings behind the patient’s responses or help the patient to learn how to ground themselves. This is the groundwork for later therapeutic interventions that will utilize the patient’s interoceptive and
introspective processes to help promote and test for changes in meaning.

Grounding, interoceptive, and introspective work always begin in a one-on-one setting. Once the patient masters these processes, interoceptive and introspective work can be moved to the peer group and family. Once the MEND therapist believes the patient has the skills to experience accurate interoception and introspection, then the therapist can use these skills in a group or family setting, where experiences are in real time. The MEND therapist will set up many of these experiences, using the peer or multi-family setting to process the patient’s written work or art assignments. This task of completing an assignment, then processing the work with others, and identifying processes of meaning and congruence, will become very familiar to the MEND patient during Phase 2. Each of these tasks are designed by the therapist and connected to the patient’s illness meanings and treatment goals. Once the MEND patient learns the ability to accurately read their body’s responses to emotional processes, they can take that information and better understand and manage their congruence.

Identify and Access Unconscious Processes

Unconscious processes (such as the meaning attached to having an illness) often guide a patient’s behaviors, however the MEND therapist can gain access to them through the patient’s language which was learned during Phase One. As patient’s
language reveals their illness meanings, the therapist can begin to further explore and test the accuracy of these meanings. MEND therapists are able to identify these unconscious processes through paying attention to psychogenic cues as patients attempt to achieve congruence as they discuss their illness and associated meanings.

In order to accurately identify psychogenic cues, the MEND therapist should have a solid template for the patient’s baseline behaviors and psychogenic responses to emotions from the extensive language learning done in Phase One. For example, if a patient states that he or she is responsible for “overburdening the family” as a result of his or her illness, the MEND therapist would expect to see the congruent psychogenic markers (e.g. flushed complexion and lowered gaze) congruent with the implied feelings of shame. While each patient’s psychogenic response to a particular meaning or emotion is different, it is impossible for the patient to congruently experience these meanings or emotions without the associated psychogenic responses.

Once the MEND therapist is able to distinguish congruent meaning actuations and emotional responses, he or she will use this information in later phases to structure interventions that will facilitate the changing of the patient’s negative illness meanings. Using the example above, the therapist’s ultimate goal would be to solicit adjustments to the patient’s meaning of being responsible for overburdening the family. Such adjustments may include, for example, giving
up responsibility for the family’s financial or emotional well-being and accepting the role of “child” (rather than “parent” or “caretaker”) in the family system. Throughout this change process (described more in Phase Three), the MEND therapist will be able to test these changes in meaning, by paying attention to changes in the patient’s psychogenic responses. As the patient gives up responsibility for the family’s financial hardship, the psychogenic response associated with an illness meaning of being “overburdening” will decrease and eventually extinguish.

**Step Two: Language Development**

Once patients are successfully able to use interoception and introspection to determine when their bodies are trying to tell them something via internal physical cues, the next phase of treatment includes developing a verbal language with which to express these cues and needs. In MEND, this process is referred to as finding a “voice.” Voice does not refer to the patient’s ability to speak their thoughts aloud since many children with chronic illness are comfortable conversing, especially with adults. Instead, voice refers to the use of verbal and behavioral language which accurately expresses the child’s needs, hopes, and fears. Through this process, the patient recognizes and voices the actual or perceived burdens which were created by their illness meanings and how they kept them from getting their needs met in healthy and adaptive ways. Patients begin recognizing their voice,
understand how this voice can be used as a more effective way of getting their needs met, and practice using their voice within the peer group which later translates into getting their needs met through more healthy and adaptive ways from others in their life.

It is important to note that during this Step, the child’s voice is likely to vary from a place of congruence to a place of incongruence with some regularity. This is a normal part of the process, and the MEND therapist should continue their stance of only placing energy in areas of congruence. Overall, the primary goal of the patient in this Step is to begin developing and practicing their voice, initially with the therapist and then with the group.

Goals of Step Two

- **Burden Identification:** Begin recognizing and voicing the actual or perceived burdens which were created by their illness meanings, and which continue to keep patients from getting their needs met in a healthy and adaptive way.

- **Voice Recognition:** Begin recognizing their “voice”, and how this voice can be used as a more effective way of getting their needs met with the therapist.

- **Practice Using Their Voice:** Practice their voice within the peer group as they transition from a passive or mentee role to
a more active role as a mentor or power broker. This process may also include accepting feedback from group members as the group processes shared histories, fears and illness meanings.

**Burden Identification**

For the MEND patient, burdens are portions of the patient’s illness meaning which are causing distress and maladaptive coping and behaviors. A child with a chronic illness often experiences feelings of being a burden, such as being responsible for the family’s happiness or working to prevent stress within the family system. Much of the time these burdens are not part of the patient’s conscious process, yet they are frequently the underlying cause of the patient’s maladaptive behaviors. The MEND patient often attempts to carry these burdens alone and when they find themselves unable to do so, they generate maladaptive behaviors to alert and solicit support from the surrounding relational system. While many of the burdens that patients carry have been identified by the therapist during the process of language learning and congruence, at this stage of treatment the overt identification of these burdens by the patient provides confirmation for the team and is used as education for the patient and their family. Illness meanings are often the most obvious of burdens for patients, and, once identified, their influence on the system can now be processed and tested.
At this point, the MEND therapist will test for changes in the influence of the burden on the patient and family system. The therapist may choose to assign a therapeutic activity (e.g. a love letter to a parent) in order to determine whether or not the patient’s language continues to contain the burden of being responsible for the family’s emotional well-being. While processing such an activity the therapist would pay special attention to the patient’s psychogenic responses whenever the patient makes a statement related to the identified burden (e.g. “I am sorry for making you worry about me.”) The MEND therapist would similarly pay attention to the parent’s psychogenic response to the activity in relation to the identified burden. For example a parent may respond to the child’s stated feeling of being a burden “I am sorry for making you worry about me” with a statement that may diminish the burden, such as: “It is ok for me to worry about you” or a further coauthorization of the burden, such as: “I know you will take better care of yourself in the future.” Processing the identified burden allows the MEND therapist to observe how the burden is expressed through congruent mind-body expression which will be used to track change in its expression over time. As perceived burdens dissipate, somatic complaints and maladaptive behaviors will also be eliminated.

**Voice Recognition**

Recognizing changes in meaning and learning healthier ways of getting developmental or
emotional needs met can be tracked through changes in patient and family members’ voice. Changes experienced in a patient’s voice indicate changes in meaning and needs-directed behavior. In the simplest terms, it’s the patient’s language moving from that of “victim” to “survivor,” or “incapable” to “masterful.” While the MEND therapist uses changes in the patient’s voice as an indicator of the alteration of meaning, it is during Phase Two that the MEND therapist will begin using the term “voice” and will evidence the patient’s use of voice to the patient, their family and the group. For example, a child may use a maladaptive behavior, such as anger outbursts, to get their need for attention met within the family or academic system. As the child begins to use their voice in a more direct and assertive manner to get this need met, the anger outbursts begin to disappear. As the patient begins to use her voice to get her needs met, it is important for the therapist to encourage the use of this appropriate and congruent behavior through praising the patient for the appropriate use of voice and to elicit similar praise from peers and family members.

**Practice Using Voice**

Once the patient is successfully able to use their voice with the therapist, they will begin the process of practicing this newfound voice within the peer group. It is important to remember that proper use of voice is a skill which requires practice in a supportive setting before it can be practiced
within a less forgiving setting, such as the family, social, or academic system. Practicing proper use of voice within the group also allows the patient to practice using an assertive voice with peers.

As patients work their way through this process, the MEND therapist will need to assist them by carefully regulating peer group processes. Specifically, regulating the patient within the group process requires the establishment of three things:

1. The social acceptance of the patient into the positive peer culture.
2. The patient’s acceptance of their position within the peer group.
3. The patient’s willingness to accept the group’s influence on their own therapeutic process.

As the patient becomes more comfortable using their voice within the group, he or she takes a role in the success of others by giving feedback to peers on their efforts in treatment. A patient’s effort and role change within the group can be used by the MEND therapist as an indicator of the patient’s progress in treatment and role development within the group. For example, as patients begins using their new assertive voice within the group, it is common for patients to transition from a passive role in which they accept the influence of the mentors and power brokers, to a more active role in which they become the new mentors and power brokers of the positive peer culture as new members are introduced to the MEND process.
Once the patient has become integrated into their role within the group, the MEND therapist can use the individual patient relationships within the group to actuate group processes. In doing so, the therapist will use the group’s influence to help move patients in healthy directions. The simple intervention of soliciting the help of a more influential peer can help the therapist move a stuck or resistant patient in the intended direction. For example, if a patient is finding it difficult to accept a suggestion from the therapist, the topic can be offered to the group as a discussion where the patient will be less likely to debunk experiences expressed by their peers.

**Step Three: Congruence**

Once the patient’s language has developed to a point where they can use their newfound voice with both the therapist and peers with no visible stress response, the patient is ready to be moved towards congruence in all domains of their life. While the move towards congruence is incremental and regressions are common, the primary goals of the MEND therapist and patient during Step Three include developing congruent language in all domains of the patient’s life, both individually and systemically. This will also include practicing the patient’s voice and congruent language with the family system in order to fulfill the patient’s needs in new and more adaptive ways. In addition, the patient continues the process of connecting their emotional processes with their psychogenic
responses and separates psychosomatic issues (e.g. exaggerated pain) from the true somatic experience of the patient’s illness. Moving the patient toward constant congruence is a continuous progression that lasts the remainder of the treatment process.

Goals of Step Three

- Developing Congruence: The development of congruent language in all domains of the patient’s life, both individually and systemically. This will also include practicing the patient’s voice and congruent language with the family system (described more in Step Five) in order to fulfill the patient’s needs in new and more adaptive ways.

- Continued Psychogenic Connections as patients connect their emotional processes with their psychogenic responses.

- Separate Psychosomatic Issues: The separation of the patient’s psychosomatic issues (e.g. exaggerated pain) from the true somatic experience of the patient’s illness.

Developing Congruence in All Domains

By this stage of treatment, the patient should understand that congruence represents the accurate expression of the patient’s internalized illness meanings through verbal, nonverbal, and behavioral language. In fact, it is common for patients to begin using this term in peer group to point out when others in the group are avoiding areas of
congruence. Once the MEND patient learns the ability to accurately read their body’s responses to emotional processes, they can take that information and better understand and manage congruence with others. Once the MEND therapist believes the patient has the skills to experience accurate interoception and introspection, then the therapist can use these skills in a group or family setting, where experiences are in real time. The MEND therapist will set up many of these experiences, using the peer or multi-family setting to process the patient’s written work or art assignments and identifying processes of meaning and congruence. Through these assignments, the therapist will work to identify the patient’s unconscious psychogenic cues and design targeted interventions to connect them to the patient’s illness meaning and treatment goals. The MEND therapist will also watch for possible points of intervention when the patient expresses congruence in areas that may not be adaptive. For example, if a patient is observed as congruent while expressing the feeling of being responsible for his mother’s stress, a follow-up intervention should be given to allow the patient to further process this perceived burden.

Continued Connection of Emotions with Psychogenic Responses

As the therapist orchestrates interventions in an attempt to connect the patient to the emotions behind their psychogenic responses to meaning, the therapist will “hold the patient” (i.e. keeping the
patient mindful of their emotional processes) in any place where congruence is observed. Holding the patient in a position of congruence can be difficult, as patients generally avoid remaining in the moment with emotions that are unpleasant. In fact, it is the need to avoid negative emotional processes that frequently leads to psychosomatic complaints (described below). However, asking the patient to stay with an emotion allows the MEND therapist the opportunity to help the patient connect accurate emotions to meaning. Once the patient takes the cue from the therapist and follows the connective prompts toward the emotion they are experiencing, and the meaning being targeted, then the therapist can use the identified congruence in the other domains such as peer or multi-family groups. Through these interventions, therapists pay attention to changes in the child’s psychogenic responses as these are indicators of changes in their illness meanings.

**Separate Psychosomatic Issues**

The process of connecting the patient’s emotional processes with their psychogenic responses includes the separation of the patient’s psychosomatic issues (physical pain or disability caused by mental or emotional issues, such as exaggerated pain) from the true somatic experience of their illness (actual pain). Psychosomatic symptoms are a common occurrence amongst the chronically ill and are unconsciously created as a means of getting an emotional need met. A
psychosomatic symptom is the body’s attempt to distract from other processes; the patient either consciously or unconsciously creates the symptom as a maladaptive means of getting their needs met. The MEND therapist works to differentiate between true somatic experiences and those that are psychosomatic through attuning to the child’s needs and how they are getting met.

Psychological symptoms are often the root cause of psychosomatic complaints, which need attention and distract from psychological pain. An example of this is a thirteen-year-old MEND patient who had both her kidney and pancreas transplanted about a year prior to starting the program. Before starting the program, she would get fearful in the evenings as things around the house began to get quiet. This little girl would then go to her mother and complain about severe stomach pains, and ask for her medication, a heavy narcotic, which she knew would put her to sleep until the next day when the process would start over again.

Treating unconscious psychosomatic complaints consists of making conscious to the child and family what the body is doing which results in the psychosomatic symptom losing its power. A similar process is needed when the psychosomatic complaint is conscious. Once the family is made aware of the process, it loses its power within the system, however, the MEND therapist will then need to realign how the child gets their needs met within the family system. If a maladaptive behavior is used to get a need met, and
the behavior is removed, it needs to be replaced with an acceptable behavior that also meets the need of the child. Otherwise, the body will simply create a new psychosomatic symptom to replace the discovered one. Using the example above, it became clear early on in treatment that the patient’s pain was a psychosomatic in nature and stemmed from the patient’s need for attention from her mother, who was overburdened by the responsibility of raising three children. Once the family was made aware of the psychosomatic nature of the symptom, both patient and mother agreed to spend at least 15 minutes alone with each other every day. As the patient’s need for her mother’s attention was met in a new way, these complaints of pain ceased.

Most of the time psychosomatic complaints have already been significantly tested and debunked by the patient’s medical team. However, there are times when these symptoms can become transient, and anytime a new symptom arises it should be shared with the medical team for evaluation. In some cases, a patient may have continued experiences with transient psychosomatic symptoms and this becomes a signal to the patient that their body is attempting to meet an emotional need which they need to address. Due to the complex nature of many of the illnesses experienced by the MEND patient, physical symptoms cannot go unaddressed.
Step Four: Meaning Response Testing

As patients continue to use their voice to get their needs met in adaptive ways, the therapist will begin the process of connecting how these changes in their language equate to changes in their illness meanings. To do this, the MEND therapist will assess for individual and systemic changes in language and meaning responses. For example, as a patient gives up past maladaptive behaviors (e.g. attention-seeking behavior) in lieu of voicing their needs to their parents, the MEND therapist will look for changes in mom or dad’s language about their interactions with the patient. Such a change may include a move away from constantly talking about the patient’s bad behaviors towards openly praising the patient for spending pleasant one-on-one time with mom or dad. The end result is a change in language, which moves away from a previous position of coauthorizing negative illness meanings and towards a position that supports and encourages healthy development.

As the patient’s illness meanings are addressed, the patient’s subconscious meaning responses and subsequent psychogenic activity will change as patients develop psychogenic congruence. While it is unlikely that illness meanings will be changed completely by this point, the MEND therapist will want to be aware of developing changes in meaning responses and attend to psychogenic regression processes (such as an increase in psychosomatic complaints) as illness meanings are challenged and secondary gains are given up. It is important to note that the respective
rejection or acceptance of the meaning change process are normal and should be expected as part of the treatment process.

Throughout this process, the therapist will also be encouraging and observing for successful patient process buy-in, or the acceptance by the patient of the interconnectedness of their emotional, psychological, and physiological processes. This will include getting the patient to notice and accept how their body has attempted to meet their needs in the past via maladaptive behaviors and/or psychosomatic complaints. The therapist will tailor interventions that keep the patient and their family system moving towards healthy illness meaning changes. For example, it is difficult for the child to continue viewing themselves as “broken” or “unlovable” when they are able to successfully elicit attention and love from their family system using healthy and assertive requests. The therapist will provide interventions meant to challenge these previously held illness meanings to help ensure the changes can sustain over time.

**Goals of Step Four**

- **Testing Meaning Responses**: Successfully testing and observing healthy changes in meaning responses.
- **Psychogenic Regression Process**: Managing and redirecting psychogenic regression processes (such as an increase in psychosomatic complaints) as illness meanings are challenged and secondary gains are given up.
• **Process Buy-In:** Encouraging and observing successful patient process buy-in, or the acceptance by the patient of the interconnectedness of their emotional, psychological and physiological processes. This will include getting the patient to notice and accept how their body has attempted to meet their needs in the past via maladaptive behaviors and/or psychosomatic complaints.

**Testing Meaning Responses**

Testing meanings responses, such as language and stress response, is used by the MEND therapist to gauge the patient’s progress in developing and establishing meaning changes. At this point, the therapist should have an understanding of the language used by the patient, knowledge of the patient and family illness meanings which are driving the patient’s maladaptive behavior(s), and the ability to read the patient’s psychogenic cues. With this understanding of the patient, the MEND therapist will assess meaning responses in order to understand how changes in illness meaning are impacting the patient. By testing meaning responses, the therapist receives feedback in real time which allows for them to gauge where the patient and their family system are in the change process and where adjustments need to be made.

As discussed earlier, many chronically ill children understand their illness in ways that place burdensome levels of responsibility onto themselves, such as feeling they are solely
responsible for the stressors within the family, such as relationship strain, financial burdens, parental conflict, and/or siblings feeling left out. These perceived burdens are commonly experienced by MEND patients and can fuel maladaptive stress response patterns within the child and the larger family system. If the patient believes that they are responsible for overburdening their family, then they may use the illness and the associated meanings to distract from these stressors. This may be in the form of a somatic complaint to redirect an argument between mother and father or complaining of being too sick to go to school in order to save money on gas and help relieve the financial burdens of the family. The goal of MEND treatment is to eliminate the patient’s stress responses from negative meaning through bringing the negative meanings into consciousness and bringing about more facilitative meanings.

Testing the stress levels associated with illness meaning involves triggering the emotionally charged event and testing to see how the patient and family members respond. These interventions are developed specifically to challenge inaccurate illnesses meanings which are fueling maladaptive processes. When these meanings are triggered, the patient begins the process of escalation. If we review the chart below we can see how the MEND therapist would actuate between the stimulus and actuation of the stress response and intervention cycles. Note that interventions are introduced during periods of more optimal cognitive integration. This is to ensure that the information
does not become further distorted through the process of a stress response, and allows the best opportunity for the patient to most clearly and accurately integrate new information. Also notice that the TI #1 (Treatment Intervention cycle #1) has a reduced level of escalation post intervention, and as the TI cycles continue, the patient is able to bring stress responses into manageable levels, and eventually move toward extinction. As interventions are successful at changing inaccurate illness meaning, then the charged emotional energy behind them dissipates.
Testing changes in meaning responses requires only that the MEND therapist use a patient’s congruent form of expression, and reintroduces the stressor. Congruent processes can be tested as they are experienced in a conscious state. Non-congruent expressions are brought into the congruent range through the use of interventions, such as identifying where the child experiences emotion that the therapist can read, and then coaching the accurate expression of that emotion in needs directed behavior. During testing (referred to as “turning up the heat”), if the identified stressor no longer solicits a stress response equal to or greater than the previous TI cycle, then the individual or systemic interventions are moving the patient in a positive goal oriented direction.

The process of identifying changes in the stress response requires the MEND therapist to measure three specific aspects of behavior: quality, quantity and duration. Quality refers to the type of change such as affect; cognitive changes; and psychogenic responses such as crying, color changes in the skin, changes in the patterns of speech. Quantity refers to how often the changed response is observed by the therapist or reported by patient, peer, or family member. Lastly, duration refers to how long the behavior lasts. If recovery times from the stress response begin to lessen, then the therapist can feel confident that the intensity of the response has been reduced.

Often through these intervention cycles, the MEND therapist gains insights into other coauthoring factors which can now be used to fine
tune meaning adjustments. For example, if during the process of testing an illness meaning of being worthless and the patient expresses concerns about not being able to complete their education, then this information aids the therapist in gaining insight into another layer of the illness meaning. Much of the time, illness meanings are played out and coauthored in multiple settings and so it is imperative to address the varied systems, such as academic and social domains, in which the patient is involved and may be influencing the illness meanings. Intervening on these levels will help to prevent regression of the patient to old maladaptive behaviors used to support the inaccurate illness meaning in these contexts.

The process of challenging illness meanings begins with the therapist, but is then passed on to the patient, and ultimately the entire family. Once the family is involved in the process of challenging maladaptive meaning, then second order change can be anticipated. The secondary gains identified earlier in the process of language learning can now be challenged as well. Challenges to meaning and secondary gains can be accomplished in infinite ways and is limited only by the imagination of the therapist. Testing the progress of meaning changes during this process are achieved through language changes and their levels of congruence.

**Psychogenic Regression Process**

As the change process is well under way, the MEND therapist must keep an eye on regressive
processes. Patients and their family systems are in the process of experiencing changes which alter the ways in which needs are being met and accepting responsibilities once averted by illness meaning. Patients and their family systems are now creating and getting comfortable with the new homeostasis developed. This new homeostasis offers two leverage points for second order change; the actuation and acceptance of new needs-directed behavior and the acceptance and integration of previously avoided responsibilities (which were once part of the secondary gains of illness meanings.)

Psychogenically, the body is usually the first to attempt to return to previous states of homeostasis, either by creating new psychosomatic issues or by increasing the severity of previous psychosomatic complaints. However, it is important to note that these processes are generally subconscious in origin. As such, the earlier the MEND therapist can notice and address regressive processes, the quicker patients can recommit to their growth. Also important is the learning opportunity for the patient and group alike. Now that most of the work is staged in a group process, all patients and families can learn from the regression and recommitment of others and begin to anticipate these regression processes and how they will respond.
Process Buy-In

When the MEND patient experiences congruence and the healing effects of changes in negative illness meanings, they begin to experience the MEND process as “working” for them. While some patients may not explicitly accept the underlying connection between their emotional processes and their psychogenic responses, by accepting more adaptive ways of getting their needs met and changing their language, the MEND patient is engaging in meaning change. From here the patient moves into a position to take a mentorship position to new patients in the group and collaborates with their therapist to set the remaining treatment goals and desired outcomes for themselves. The patient also assists in gaining further buy-in from their family system due to the family witnessing the positive changes in the patient and thus being more willing to accept the MEND therapist’s suggestions in initiating additional second order change within the family system.

Step Five: Systemic Adjustment

At this point, the therapist will further solicit the family’s involvement in the change process. Here, the family will join with the therapist to begin practicing positive behavioral support and to learn how not to place energy which coauthors maladaptive illness meanings. In addition, guilt and shame in the parenting process are addressed. With
the therapist, the parents work toward placing energy that supports the patient’s movement toward healthy needs-directed behavior which will positively affect the patient’s physical health.

Goals of Step Five

- **Family Identification and Movement Away from Needs-directed Behavior (power):** Learn how to create second-order change by moving energy away from the patient’s maladaptive use of power in the family system and towards the patient’s use of new adaptive needs-directed behavior and voice.
- **Therapist-Family Collaboration:** Begin to work within the collaborative therapist-family relationship, including exploring new, healthier ways to support the patient’s healing process.
- **Parent Support:** Find support and validation within the Parent Support Group.
- **Identify Guilt and Shame Processes in Parenting:** Identify and address ways in which the parent-child relationship.

Identification of Power

As the patient’s family begins to learn how their actions and behaviors affect the patient’s illness meanings, the MEND therapist will share with the parents the patient’s learned language and areas of systemic power, learned during Phase One. The coauthoring process is also revealed, and patients and family members learn how their behavior has created or perpetuated the very
maladaptive processes which have been identified as unhealthy emotionally, systemically, and physically. This has to be approached by the MEND therapist in the most constructive and supportive way possible for the system to change. As such, it is important to remind parents that they have failed neither themselves nor the patient by coauthorizing the patient’s process. Simply put, they have reacted to a terrible situation in a way that they assumed would keep themselves and their family safe and healthy. While this underlying assumption was incorrect, it is the behaviors that are flawed, not the parents’ intent.

**Therapist-Family Collaboration**

As the MEND therapist shares pieces of how their child has learned to get their needs met and avoid the burdens of negative illness meanings, the parents learn how to support healthy processes at home. Since the parents have achieved buy-in to the MEND program, they are willing to collaborate with their therapist in continuing interventions as homework. By creating a healthy and supportive family environment the therapist is able to facilitate the fastest change process in the model. This rapid change in systemic functioning is due to the foundation of individual movement by the patient and preparation of the parents by the therapist during the previous steps.

Once the family system is ready to attempt implementing systemic changes at home, the first step is to have the parents simply give no energy to
the patient’s attempts to get their needs met in maladaptive ways. For example, parents are told that when their child complains of a psychosomatic issue, they should not respond to the psychosomatic issue, but instead respond to the child’s emotional content (e.g. anxiety) which is displayed behind the psychosomatic complaint. As parents have been given insight into the patient’s use of negative illness meanings as a form of power within the family system, parents should no longer be influenced by that power. Often the MEND therapist will role-play or talk through this process for the parents. This allows the parents to anticipate responses by their child and have answers for any resistance. For example, parents are often told to expect an escalation in maladaptive behaviors when the patient finds that their previous behaviors are no longer effective. By anticipating this escalation, parents are able to respond with appropriate neutrality rather than default to past coauthorizing behaviors (such as shaming the patient.)

It is important to note that the therapist should give this homework for the first time on a day where the family will return within 1-2 days to report and process the results. If the family goes home and hits roadblocks without access to the therapist, the roadblock can cause undue stress and even promote the regression process. However, the MEND therapist will have primed both the patient and the parents separately for such an exercise by providing opportunities to experience success through smaller, preliminary issues before working on larger systemic changes. These initial successes
give collaborative energy to the process and reduce the chances of future regression.

**Parent Support**

While much of the work done in the MEND program focuses on the patient, it is important to also provide parents the space necessary to heal and grow. Two days of the week, the last hour of treatment is reserved for multi-family group. However, one day per week (preferably the middle day of treatment) the parents should come together for a Parent Support Group while the patients are engaged in another process (e.g. occupational therapy). The purpose of the Parent Support Group is to allow a space where the parents of chronically ill children in the MEND program can come together and discuss issues associated with their unique parenting roles. Here the therapist will offer some psychoeducation as needed to support the parents’ process, however the group should be fairly interactive and self-supportive. The senior group members should share their experience, strength and hope with newer members, while newer members should be encouraged to discuss personal issues (such as guilt) which are impacting their child’s treatment.
Identify Guilt and Shame Processes in Parenting

One topic common to the Parent Support Group is the destructive influence of guilt and shame on the parenting process. Parenting inherently comes with struggles and difficulties, but a child with a chronic illness and the associated strains can be especially challenging and cause the parents to question many aspects of personal and parental ability and function. Parents experience guilt because they often take responsibility for their child being sick and feel ashamed because of negative or resentful feelings toward their child for not being the healthy child they had hoped for. Guilt and shame are often presented to the MEND parents as being poison that a parent takes and which makes their child sick. Once the parents learn how their guilt and shame can negatively impact their child, they are generally willing to work with their therapist to eliminate them from parenting processes. In addition, hearing from other parents that they too have some of the same struggles and experiences gives them a sense of community and helps to normalize their unique position as parents of a chronically ill child.

Phase Two Milestones:

By the end of Phase 2, the MEND patient has made significant progress towards giving up past maladaptive behaviors and accepting new ways of getting their developmental and emotional needs met. Patient have begun to learn about the mind-
body and practice the skills of interoception and introspection and will begin noticing the connection between accurate, congruent emotions and their associated psychogenic cues. Patient will begin recognizing and voicing the actual or perceived burdens which were created by their illness meanings, and which continue to keep patients from getting their needs met in a healthy and adaptive way. However, it is important to note that by this point, no second order change has occurred and negative illness meanings have only begun to change. While it may be tempting to assume that the patient will be able to continue their healing process on their own, or in individual therapy, such early terminations are likely to result in little to no lasting change.

As the patient nears the end of Phase Two, the role and posture of the MEND therapist begins to change from the professional driving the process, to more of a coach and cheerleader. At this point in treatment, the patient has completed a considerable amount of work to make alterations in illness meanings that were previously identified as inaccurate, negative and causing the actuation of the stress response. As the patient develops insight and provides feedback to their peers, they become senior members and power brokers in the group. Throughout this process, the MEND therapist will enthusiastically champion these positive changes and gauge the patient’s integration of healthy needs-directed behavior. The enthusiastic championing by the therapist promotes the power broker position of the patients who are progressing strongly in the
program. Moreover, it sets an example for the other patients and families by providing a positive view of illness meaning change.

As the patient enters Phase Three, the family will start using the process to create and implement their own systemic adjustments. It is assumed by this point that the patient has begun the process of illness meaning change, and has also begun to use more appropriate needs-directed behaviors with the family. As the family system moves through Phase Three, it too should begin the process of accepting and encouraging illness meaning change. While the family’s process during Phases One and Two have largely been that of a supportive role of the patient’s change, the system will be asked to take a far more active and controlling role in Phase Three. It is important that families learn how to maintain healthy processes, and one of the primary goals for the MEND therapist should be to give families the tools necessary to maintain their own healthy processes. This second-order change is vital to the patient’s success beyond graduation from the program, and additional time should be spent managing regression processes within the family system as needed.
PHASE III – MEANING AND EXPRESSION

Step One: Creating Changes in Meaning
Step Two: Systemic Acceptance of Change

Phase Three contains two specific goals: creating changes in meaning and teaching the patient and their supporting system how the use of expression, conscious and unconscious, is being altered and used to progress toward healthier processes. In this phase, the therapist shifts the focus from teaching and learning the child’s stress response patterning to considering the effects of the change on the larger family system as well as the larger context in which the family exists. More specifically, the therapist will reevaluate whether the family system is able to respond in new ways toward the child when the child seeks to have his emotional needs met. It is important for families at this point to support the development of healthy needs-directed behavior and self-management skills even if such behavior is initially beyond what is considered acceptable for the family system. For example, whereas a child in the past may have exaggerated symptoms to get his mother’s attention, the child would now be encouraged to directly ask for one-on-one time with his mother. If the therapist is able to help prepare the family for these changes, the child will receive consistent acceptance in their growth and the changes are likely to continue.

Once the therapist is confident that the family system has realigned to the new stress coping
processes and changed meanings about the illness, she will shift to explore and test for evidence of sustainability of the changes. Testing sustainability involves the therapist intentionally stressing the system to determine whether new or additional stress can be experienced by the child and family without the system reverting back to old maladaptive beliefs, meanings, or stress response patterns. In this case, the therapist hopes to see that new skills are mastered not only by the child but also by the family system. Specifically that maladaptive meanings, identified in phase I, have changed and the family becomes more supportive of the child’s continued age appropriate developmental progression. In addition when the therapist, through the process of sustainability testing, sees that the individual and their system are using the new skills acquired in phase II consistently over time, the therapist can feel confident that the system will be able to successfully move forward and meet challenges after the end of the MEND program.

**Step One: Creating Changes in Meaning**

Changing illness meanings requires the culmination of the knowledge and skills learned by both patient and system during Phases One and Two. It also requires the MEND therapist to have completely learned the patient’s language, to understand the meaning of the illness to the child and family, to know what burdens are present, to see how the system is influenced by illness, to make
sense of how the system coauthors the illness meanings, and to have the support of the patient, the peers, and the family. Once all of the above has been accomplished, the therapist will help the patient move towards illness meaning change. While many of the illness meaning changes have already occurred in Phase Two, the primary goal in Step One is ensuring that such changes are stable and have been fully integrated into the patient’s belief system. Assessment of this is done through paying attention to changes in the patient’s SNS activation when exposed to previously addressed illness meanings.

Goals of Step One

- **Meaning Responses and Change**: Using the patient’s meaning responses to **gauge where meaning has changed** and which illness meanings require further intervention.
- **Continued Language Development**: Continuing to help the patient generalize the use of voice and move towards more **strength-base language** (i.e. survivor vs. victim.)
- **Testing Response Integration**: Testing the patient’s integration of illness meaning change and healthy needs-directed behaviors.
- **Physiological Response Changes**: Paying attention to **changes in the patient’s SNS activation** when exposed to previously addressed illness meanings.
Meaning Responses and Change

By this point, the meanings that have been identified as having caused individual and systemic distress can be changed. Moreover, as congruent processes are now accessible, they can be used to create interventions that accurately address specific illness meanings and burdens still present for the patient and family system. However, in order to understand which illness meanings require intervention, which have changed and which are still in the process of changing, the MEND therapist will need to pay special attention to the patient’s meaning responses.

Using the previous 13-year-old transplant patient, let’s take a look at the use of an intervention which was specifically geared to actuate her illness meaning of overburdening the family. The therapist had previously identified the tactile processes of painting and drawing as processes in which the patient often expressed congruent language. Given this knowledge of the patient’s language, the therapist requested that the patient create a picture that depicted her and her family. It is important to note that no other instructions were given, as the therapist wanted the patient to project whatever illness meanings were present for the patient at the time. Once the image was complete, the therapist noted that the patient’s family was on the front of the canvas interacting together in close proximity. However, the patient was not included in the scene. On the back, the patient had drawn
herself in significantly smaller stature to that of her other family members, including younger brothers. Sensing that the implied illness meaning may be difficult for the patient to process without resistance, the therapist offered up the artwork for feedback from the peer group. The patient’s peers were quick to ask her why she was not standing with her family. Initially, the patient tried to divert and avoid the significance of her missing presence within the created image, confirming the therapist’s belief that the patient was unconsciously responding to the actuation of one of her illness meanings.

This subconscious omission from the family scene became conscious as the therapist and the patient’s peers questioned the patient and gave feedback. The intervention was then moved to the multi-family group, where the patient again was asked to show her intervention-directed assignment. However, by now, the patient had peer-generated insight into how the image of her family was depicted and why. As the patient processed this meaning she became tearful, reporting that she did not feel a part of the family. When asked by her step-father why she did not feel like a part of the family, the patient suddenly became tearful and responded that she believed she had caused all of the problems in the family. Furthermore, the patient responded to additional group feedback by reporting that her mom was always mad at her. When asked why she felt her mother was always angry with her, the patient suddenly became angry, stating, “Because I am always sick.” This actuation of the meaning response process (or the process by
which a patient unconsciously reacts to the activation of an illness meaning) gives the therapist a lot of information in which he or she can use to gauge movement in that response. In other words, by paying attention to changes in the patient’s meaning response to a specific illness meaning, the therapist can gage whether a change in that illness meaning has occurred, and to what extent.

In the example above, the perception could be that this patient was congruent when she became tearful with the realization that she believed herself to be a burden on her family. However, in reality, this was not an accurately congruent moment for the patient. The MEND therapist, having learned the patient’s language during Phase One, could tell that the patient’s tears were incongruent based on their sudden onset (a classic sign of incongruence) and equally sudden disappearance when distracted by the therapist’s question about her mother. Instead, the therapist determined that the patient’s anger was congruent based upon the patient’s body language and previously learned psychogenic response to anger, which was present when talking about her mother. As such, the therapist determined that what the patient required was help to experience and assertively express her “voice” of anger toward her mother for treating her differently than she did her siblings.

In doing so, the therapist read the patient’s congruent meaning response to the belief that her mother treated her differently because her illness was a burden on the family. In order to create successful meaning change, the therapist helped the
patient practice her use of voice to assert her need for more appropriate interactions with her mother. The end result was the creation of at least 10-15 minutes each day in which mother and daughter spent time alone together. During this time the patient could voice her thoughts, feelings and needs with her mother in an accurate and appropriate manner. As patient and mother formed a healthier relationship, the patient’s response to exercises that elicited a meaning response to being a burden on the family diminished.

**Continued Language Development**

As the patient progresses through Phase Three, the information gained during the Language Learning Step in Phase One becomes a tool used by the MEND therapist to help make patients aware of, and empowered by, their process. The goal at this point is to teach the patient and their supporting system how the use of expression, conscious and unconscious, is being altered and used to progress toward healthier processes.

*Voice generalization*

Now that the patient is aware of how their expressive processes have been observed and reported as changing, and have been told that this process is a positive indicator of healthy growth, the patient and support system can identify and champion the effort. All those involved will be prompted to place positive validation of efforts to make these new healthier expressions a common
place. In other words, now that both patient and system are aware of the healthy need for appropriate voice, the patient’s use of voice within the family system can be supported and reinforced by sources outside of MEND (i.e. by the family system and by the patient’s internal need for competency), and the continued use of healthy and accurate voice can be generalized to other settings, such as school and normal peer interactions.

*Meaning language changes*

When language changes and expression remains congruent, then meaning has been altered. Language meaning is always connected to the negative illness meanings identified by the therapist during the Language Learning process. As the patient progresses through treatment, the MEND team continues to actuate and test the effects of the identified meanings until the maladaptive behavior and the stress responses are eliminated. In addition, the MEND therapist will continually look for changes in the patient’s language which indicate underlying changes in meaning. Specifically, the therapist will want to pay attention to, and provide reinforcement of, language changes that move away from fear-based language towards strength-based language. Some examples of such language changes include the move from:

- *Victim to survivor*: In this case, the use of tenses change from passive to active as the patient describes topics of illness meaning.
Congruence remains consistent and stress responses are absent.

- **Limited to limitless**: Verbal language becomes goal-directed and the future becomes a topic accepted and participated in, rather than feared or avoided.
- **Unworthy to worthy**: The patient places healthy boundaries and expectations on themselves and their familial and social relationships.

**Testing Response Integration**

Earlier in the manual, we described stress response testing, which is the process of seeking congruence with accurate emotional experience. In stress response testing the therapist is using the patient’s language in order to gauge levels of distress and maladaptation. In Phase Three, we test response integration in which the MEND therapist seeks congruence between patient responses which indicates that integration of new emotional and physical responses to the patient’s negative illness meaning is taking place. The congruence between illness meaning, stress response, expression, and behavior is paramount to identifying the healthy integration of all MEND principles. When this integration is achieved, the body is at the most optimal position to reduce the negative effects of the SNS: increasing cognition, information integration, and accurate memory development. Testing the patient’s responses to meaning is an ongoing process throughout treatment. Initially, the MEND therapist used this process to identify issues
of negative illness meaning and congruence. As the patient participates in treatment, the therapist will continually test the patient’s meaning responses to determine movement and progress.

Testing response integration is the process of presenting the patient with previously identified meanings, which were negative, supported maladaptive needs-directed behavior, and caused the patient to experience the SNS activation. The therapist should actuate, or trigger, these identified meanings in any of the congruent domains while assessing meaning impact, changes in meaning responses, and the level of the response integration. An example of this process in the group setting would include the therapist working with the patient’s peers on topics connected to common illness meanings and challenging the patient to defend his/her progress by aligning with a peer’s maladaptive behavior.
In this phase, the therapist is concerned with ensuring that the new reframed responses (illness meanings and subsequent psychogenic responses) are integrated totally. For the therapist this means stressing the patient and their system (described below), to see if new healthy responses are fully integrated and actuated even during times of stress. Earlier in Phase Two, the patient may have struggled to accept and actuate healthier meaning
responses, and the therapist would be charged with helping the patient solidify these new processes. Now, the patient’s responses to the identified meanings should be their go-to position, even as the therapist attempts to test it under stress.

Testing is done multiple times in this phase across multiple settings. A common example of this process involves re-introducing previously identified topics (within phase I) charged with emotional energy. In this case the child may have been dealing with depression and in phase I and was asked to paint pictures that illustrate these emotions. Here in phase III the therapist may ask the child to share the painting and its meaning with her parents or in a multifamily setting. In doing this the therapist creates an environment with greater levels of intensity. In this exercise the therapist would be looking for the child to maintain a congruent position, demonstrating new skills learned in phase II, while reporting to the family or group. Also, the therapist is also watching to see that the family does not reengage in old maladaptive stress response patterns during these exercises. Although the presentation is important, the true test comes from the therapist increasing the intensity in this exercise by interjecting challenges. Specifically the child will report meanings and emotions of the picture, but from this newly learned congruent state which they acquired in phase II. Here the therapist will ask questions or pose challenges that tempt the child to revert back to maladaptive response to emotional stress. Specifically the therapist will re-introduce previously identified and highly charged
areas of stress identified in Phase I in order to determine if the child is able to maintain his or her progress and not revert back to the old stress response patterns or old meanings (such as believing that they are a burden).

If this child and the family are able to sustain the change in the face of these challenges the therapist will turn up the heat even farther by challenging the child’s ability to reengage in school and other similar activities. For example, in a multifamily group or in a family therapy session the child might report their desire and confidence to return to school and meet new friends and be academically successful. At this stage the therapist may present as confused and question the child as to how they believe they can be successful in these new goals when they are broken or sick. The therapist will even express significant concerns that the child might not be ready to take on such a significant step. In this test the therapist is watching to see how fast the child is able to respond to this challenge without reverting back to maladaptive stress patterns or negative belief systems. The quicker the child and the family support the goal of returning to school the more solidified the change has become.

It is important to note that this process of testing the sustainability by stressing the system is not done in a harsh combative manner. It is experienced as intense and stressful, but this intensity is allowed due to the nature of the therapeutic relationship which has been developed over phases I and II.
Physiological Response Changes

By the end of Phase Three, the psychogenic cues identified within the MEND model should be reevaluated for significant changes. Compliance markers, too, should show their strongest stability to date, and any identified psychosomatic processes should be completely eliminated. While the patient may have not experienced any psychosomatic symptoms for some time, it isn’t until the end of Phase Three that the MEND therapist will declare, with confidence, that the somatic symptom has truly been extinguished. This pause in declaration is due to the stressful process of response testing. Not until the therapist reads little to no stress (or SNS activation) in the patient’s meaning responses can they be confident that somatization processes are extinct. Declaring somatic relief too early, only to have the somatic complaint return when the therapist stresses the system, may cause regressive processes.

Step Two: Systemic Acceptance of Change

While the family’s process during Phases One and Two have largely been that of a supportive role of the patient’s change, the system will be asked to take a far more active and controlling role in Step Two. It is important that families learn how to maintain healthy processes, and one of the primary goals for the MEND therapist should be to give
families the tools necessary to maintain their own healthy processes. Changes in the family system in Phase Three are rapid and predictable which gives the therapist leverage as they can accurately give patient-response information to the family. As changes and challenges play out as predicted, the systemic buy-in is strengthened, and momentum is gained. In Phase Three, the MEND therapist introduces all of the identified leverage points in the actuation of second-order change. This is the point in treatment where the therapist prepares the family system for the creation of a new equilibrium.

Goals of Step Two

- **Predict and prepare** the family for upcoming challenges, as well as their routes to growth and success.
- **Test the family for systemic changes** in illness meanings, as well as for the elimination of negative coauthorization processes.
- Establish appropriate systemic **buy-in and integration** of the MEND model
- Help parents to **reorient their identity** to include meanings outside of being the “parent of a sick child.”

**Predict and Prepare**

Responses toward meeting the new, healthier needs of the MEND patient must be of acute importance. If the system wishes to make the patient’s positive changes in needs-directed
behavior permanent, then the positive response to those needs must be quicker and more consistent than the previous maladaptive ones. This may be difficult for parents, who are already overwhelmed by their own stressors, to manage. However, it is important for the MEND therapist to help the family find ways to make appropriate changes. Children will always respond in a way that meets their needs fastest. A great example of this is when one parent is more willing to respond to requests by the child. These “nice” parents quickly become the patient’s go-to person for requests, while the “mean” parent is only used as a last-resort.

Accepting and regulating patient voice within family values

It is also important for families to support the development of healthy needs-directed behavior, even if such behavior is initially beyond what is considered acceptable in the family system. For example, during Phases Two and Three, MEND patients develop changes in their expression of illness meaning via their newfound voice. The development of voice may be identified by the family as overtly disrespectful. However, as the child practices their voice within the family system to get their needs met, and the family system responds appropriately, the child’s voice will become more accurate to their needs. If the family understands the type of struggles the patient may experience during this process, then the chances are better that the parental position will not be punitive, which could stifle the patients attempts at growth. The MEND therapist will also need to educate the
parents on styles of learning, and solicit the family to adopt a shaping style where the focus is on the goal and not the mistake. If the therapist does a good job of preparing the family for alterations in their child’s process, and the child receives consistent acceptance in their growth, then voice development will be experienced as accepted. The MEND therapist can then use family and multi-family groups to process how this voice development is accepted and integrated into the family system.

**Test the Family for Systemic Changes**

Systemic stress response testing parallels the response testing process for the patient, described in Step One. Here however, the MEND therapist will focus specifically on the actuation of maladaptive systemic rules and processes that perpetuated the circular causality of coauthorization. Identifying leverage points within the system to promote changes in homeostasis is a process that was completed in Phase Two. In Phase Three, the therapist’s role is to coach the system through the change process. In particular, the MEND therapist should be aware of changes in the process of coauthorization within the family system. How the changes are integrated is identified through the process of response testing.

As meaning is altered and tested for healthy change and integration, the MEND therapist should experience changes in the patient’s attempts at coauthorization. No longer will the MEND patient
choose behaviors which require responses that reinforce illness meanings. As the patient’s illness meanings change in Phase Three, the need for healthier responses from all systems will become universal. It is important to remember that coauthorization will always be a process of a child’s development. However, what is important for healthy development is accurate meaning reciprocity. In other words, coauthorization itself is neither positive nor negative. What the patient requires for healthy development are coauthorization processes which are accurate to the strengths and limitations of the patient.

**Systemic Buy-In and Integration**

With all of the progress experienced by the patient, and the collaborative relationship between the therapist and the family, the family’s buy-in becomes solidified in Phase Three. Any pushback in the systemic buy-in process by the family is usually contributed to the parent’s struggles to retain control of the family system. The MEND therapist may need to help the parents realign their principles to better support the promotion of health. While systemic buy-in of the MEND model of illness meaning change is not a requirement for graduation, the MEND team is likely to experience less regression processes and longer-lasting results with those families who experience systemic buy-in.
Reorienting Parent Identity

Lastly, it is worth mentioning that many parents who struggle with systemic buy-in do so because of a fear of losing their identity as the parent of an ill child. This is an important concept because, for many parents of a chronically ill child, socialization and identity becomes tied to the illness process. For many parents, there are comforts in this position as it gives meaning and a sense of nobility as caregivers. As the MEND patient becomes healthier, the parental identity must also make adjustments so that it doesn’t influence the child into regressive processes. On many occasions the MEND team has experienced parents who maintain their identity at their child’s expense. While much of the process of developing a new parental identity takes place in the parent support group, the therapist will also need to assist resistive parents in regaining their individual self. To reinvest in the individual goals and interest which were put on the shelf when their child became ill. One common intervention is to have the parent find some time to focus on individual care versus care for the child.

Phase Three Milestones

By the end of Phase Three, families demonstrate systemic changes in illness meanings, as well as the elimination of negative coauthorization processes, demonstrate appropriate systemic buy-in and integration of the MEND model, and parents are able to reorient their identity.
to include meanings outside of being the “parent of a sick child.” Families are prepared for upcoming challenges, as well as their routes to growth and success. While the majority of the patient’s movement towards healthy meaning change occurs during Phase Two, the family system’s movement primarily occurs during Phase Three. This second-order change is necessary for long-term illness meaning change, and often supports healthy patient development beyond the scope of illness meaning and into areas of normal child development. The acceptance of appropriate voice and healthy needs-directed behavior sets the stage for better parent-child relationships and appropriate individuation as patients move towards young adulthood.
PHASE IV – CHANGE GENERALIZATION AND REINTEGRATION

Step One: Changes beyond the individual and system

Step Two: Identification and integration of supportive services

Step Three: Graduation

Step One: Changes beyond the individual and system

The final phase of MEND focuses on the integration of all the learning and development experienced by the patient and their system into all areas of life, such as the patient returning to a regular academic setting, returning to activities previously enjoyed, or the transition of responsibility for the patient’s medical processes from parent to patient. During this phase the family acknowledges that they have made a significant change and also expect and prepare for those times of greater stress when they may fall back on old maladaptive processes. While meaning change has occurred for both the patient and their family system, the transition back into normal daily living is fraught with challenges and the potential for regression processes. To safely observe and somewhat guide these inevitable situations, the therapist will help the child reintegrate into their
academic and social environments. This is a time where (if the child has been previously out of school due to his illness) the therapist will work with the family, the medical team, and the school to reengage the child back in school. This is often a significant stressor for the family and a key indicator that the family either is or is not ready to conclude the program. Finally, the MEND therapist creates a discharge plan with the family. While each plan is unique for the child and their chronic illness, common elements include: a time of reflecting with the family about the progress they made; reminding them to expect future stress; and preparing them to identify, acknowledge, and respond to these events.

**Step One Goals:**

- **Set-Up Challenge Responses** Help the patient and their system anticipate common challenges associated with the reintegration process and work with the patient to come up with appropriate responses to maintain health development and meaning change.

- **Adjustment and Reintegration into Healthy Development** Provide appropriate referrals for ongoing care, as needed, and prevent any attempt to regress in order to stay in treatment.

At the start of Phase Four, the MEND therapist begins the discharge planning process, and if referrals are warranted, they are given with the assignment of scheduling appointments prior to graduation. Discharge is discussed at the beginning
the fourth phase not simply to give family time to make any necessary referral appointments, but also to give the MEND therapist time to work through any efforts by the patient to regress and stay in treatment. For many of the children in the MEND program, chronic illness has taken them out of normal activities of social development. Being faced with the process of leaving the program can cause the patient to report old symptomatology in an attempt to stay in treatment and remain within the safe social environment developed by the MEND therapist and peer group.

During the treatment process, the child becomes more congruent with their emotional content in regards to their illness, which in turn changes the meaning of the illness for the child. The child begins to recognize that their illness is only a component of their identity and has the ability to develop a life worth living outside of their illness. As treatment progress through phase four, the child will have mastered many areas that will provide them the ability to positively function in all domains of life. With these new skills, the child will be able to integrate their illness into their day-to-day routines without significant stress responses to the illness, which will be a good marker for the MEND therapist to evaluate full healthy integration of the child’s illness. The child at this point should be adhering to treatment regimens because the child has the ability to recognize the value in maintaining their illness in a healthy manner. The MEND therapist will check in with the patient and family about the child’s treatment adherence as well as
utilize lab results to measure necessary levels of medication or assess for overall healthier lab results. In addition, the MEND therapist will help the family and patient troubleshoot any foreseen complication after the end of treatment.

**Set-Up Challenge Responses**

In order to be sure that the patient is ready for graduation, the MEND therapist will often set up challenge responses, which is referred to in the MEND model as “playing the tape all the way through”. Here the therapist works with the patient and their family to process anticipated challenges and, together, to decide on acceptable responses which will keep the patient and family on-track. Meaning the therapist, patient, and family brainstorm potential obstacles and anticipated challenges that may shift homeostasis back to its maladaptive patterns. The challenges potentially experienced by a family can be unique to them, or processed as a common experience for many families. For example, how should the patient respond when peers ask about his or her insulin injections? The therapist can use family or multi-family settings to process challenges with the greatest benefit coming from multi-family support and parent support group.

The therapist and patient will discuss possible challenges within the peer group and acceptable responses to these challenges. Every ill child will have different potential challenges they may experience, but having a plan on how to respond to
these challenges will allow the child to feel competent and self-assured in their ability to cope with these challenges if they do arise. In addition, the family system may also have concerns about the challenges that may potentially occur. The therapist may use the multi-family format or parent support group to help process these challenges and help the families respond to these challenges in a healthy adaptive way for the child. Some of these challenges may be based out of the family system’s fear of the child returning to maladaptive behaviors and these conversations should be had without the child present to ensure the child’s progress and eliminate the coauthorization process.

Challenges for the chronically ill child can come from all domains, which were identified as playing a role in their development of negative meaning or the coauthorization process. This could mean challenges with their medical team, academic setting, extended family, and socialization environments, who may want to maintain the original maladaptive behaviors to maintain homeostasis within the ecological system. Therefore, the therapist should sit with the family and patient individually and together to help troubleshoot potential challenges to help maintain the new healthy homeostasis developed. In addition, having referrals for the family and patient to utilize after treatment has ended is also essential in helping keep the family and patient accountable and moving forward.

*Challenging the Patient’s Progress*
As a patient progresses through the MEND model and treatment is ending, challenges are set up to evaluate and test the patient’s progress. Patient’s progress is determined by changes in their language, changes in the meaning of their illness, and extinction of their stress responses. Particularly with a patient with a chronic illness, the meaning of the illness is assessed through the usage of the new language learned and changes in their psychogenic cues. As the patient’s meaning of their illness has changed their language will present with more healthy verbal responses, such as more emotional congruence when talking about their illness and other areas they may have struggled. In addition, their psychogenic cues will present more at ease and demonstrate less of a stress response or extinction of the stress response all together. These challenges are presented by the therapist to assess the patient’s progress throughout treatment, but are essential during phase four to determine when graduation from the program will occur.

As mentioned earlier, during treatment patients are asked to let go of the secondary gains from their illness (i.e. not going to school due to their illness or presenting as broken to avoid developmentally appropriate responsibilities). Once they have let go of their secondary gains to develop healthy adaptive behaviors, these new healthy behaviors are tested to assess the patient’s integration of these behaviors. For example, many chronically ill children use their illness to avoid school because they feel the socialization component of the academic setting. As they gain
confidence in their developing socialization skills within the peer group, they in turn are encouraged to return to school to utilize these newly developed skills. As they reintegrate into school, patients are then challenged within the therapeutic peer group to help other patients fit in to continue to practice these socialization skills and allow the MEND therapist to evaluate the patient’s progress and meaning changes. In addition, the child’s language and psychogenic cues are concurrently assessed as they help others master these skills. When the child responds in a healthy adaptive manner and no longer uses the illness to avoid school then it can be assumed that the meaning of their illness has changed and the child has integrated and mastered new healthy behaviors.

Adjustment and Reintegration into Healthy Development

Once appropriate challenge responses have been developed, the patient is ready to begin the process of reintegration. To begin this process, the MEND therapist will position the patient in situations designed to sharpen appropriate social and development skills. Response testing can also be used to assess the accuracy of the intervention. The solicitation of the patient’s peers and family in this process goes a long way, as the patient is trusting of their support. Reintegrating or introducing the MEND patient into positions to develop in healthy ways often requires the involvement of the very individuals and systems
which had previously participated in negative illness meaning. The MEND therapist should participate with the patient and family in taking steps toward activities and relationships which are developmentally healthy.

The chronically ill child tends to be at greater risk for developmentally arresting traumas and experiences than their healthier peers. Chronically ill children also experience greater levels of stress; stress responses can be physiologically harmful, and can negatively affect the process of treatment and recovery, and disrupt the patient’s quality of life. In addition, chronically ill children are usually removed from settings that are pro social and promote social development, which are essential developmental tasks for all children. Chronically ill children also tend to be poorly equipped to manage age appropriate tasks due to their illness and therefore may experience a significant stress response when asked to manage or engage in age appropriate tasks (i.e. socialization).

During phase four, the chronically ill patient is encouraged to reintegrate into healthy development, to ensure full adjustment into healthy adaptive behaviors. It is the job of the therapist to assess adjustment and reintegration into healthy development. One way the therapist accomplishes this is evaluating the language change. Because the MEND therapist spent most of phase one learning the child’s language and its meanings, changes in meaning are determined by the changes in the child’s language, which include changes in the child’s psychogenic responses to psychosocial
stressors. The therapist uses the language as a marker to identify integration of healthy adaptive behaviors and progress of change in the illness process.

As treatment progresses, the MEND therapist will also, position the patient in situations designed to sharpen appropriate social and developmental skills. Patients will be aligned with patients who are new to the peer process and asked to help integrate these incoming patients. The use of language, peer process feedback, and social skills will give the therapist evidence to whether the child has fully incorporated and adjusted themselves into healthy developmental tasks such as socialization. Response testing can also be used to assess the accuracy of the interventions implemented. In addition, during the multifamily format, solicitation of the patient’s peers and family in this process will support the patient’s changes and help with continued validation and promotion of healthy adaptive behaviors.

Another area of integration into healthy development for a chronically ill child is managing their illness in an age appropriate healthy manner. For chronically ill children that means medication compliance and maintenance of medical regimen. The MEND therapist will assess medication compliance and healthy behaviors in regards to medical health. The therapist will also solicit the family system’s feedback on how the child is maintaining their medical needs at home. If the child is reported to be maintaining their medical needs appropriately and does not demonstrate a stress response to the assessment by the therapist,
then it can be assumed that the chronically ill child’s medical needs have been adjusted and integrated into healthy development.

**Healthy Bio-Psycho-Social Development**

Reintegration into healthy development requires participation from all the systems that engaged in developing negative illness meanings for the chronically ill child. These bio psychosocial systems usually consist of family, peers, medical teams, school settings, etc. The MEND therapist will participate with the patient and family in taking steps toward activities and relationships, which are developmentally healthy.

**Academic**

One of the most common areas of reintegration for the MEND patient is the move back to school. While the academic setting can prove to have some real benefits to social development, academic settings can be a system that coauthors a child’s illness as they may perceive or demonstrate to the child that their illness is a liability that renders them incapable of being academically accomplished, which can then lead to self or system removal from the normal academic curriculum and flow. Academic leadership may also place restrictions or develop accommodations for the child’s illness, which may not be necessary. The child then perceives themselves as damaged or incapable of being successful in their academic pursuits. Much of the time, due to perceived liabilities, the school leadership often places more
restrictions on the student than are necessary. This may include decreased expectations about the patient’s quality of work, or unwarranted placement in resource classes. The MEND therapist can work with the patient and family to express expectations of collaboration in creating the healthiest educational environment as possible.

As treatment progresses, the MEND therapist, child, and family can work in collaboration to understanding and creating the healthiest educational environment possible. This usually includes determining whether the child should attend regular school, which includes a social component that is necessary for healthy social development, or another educational program that will help the chronically ill child feel as accomplished and capable as possible. In addition, evaluation of the accommodations originally made for the child should also be examine and re–evaluated to determine if they are necessary or they are restricting the child from feeling capable to continue their schooling.

It is also important during this phase of treatment for the parents and MEND therapist to problem solve and troubleshoot any of the family’s possible concerns for child, outside of the child’s presence. It is necessary for the child to perceive themselves as capable of being able to return to their academics and accomplish their goals without the interference of their family’s concerns. Otherwise, the patient may regress into previous meanings and behaviors to return the family to their original homeostasis, which may ultimately not
allow the child to return to school, which is a healthy part of any child’s development. It is recommended that the child should remain in treatment as the child transitions back to school, to help the child and family find a new homeostasis. This also provides the child and family a support system through the peer, parent, and multi-family format of therapy.

**Friends**

A child and adolescent’s number one developmental responsibility is socialization/fitting in with peers. Chronically ill children may appear as well socialized due to their significant exposure to adults and well developed language due to this exposure, however, when placed with a group of peers their own age they have difficulty interacting. As a chronically ill child continues through the MEND model, the peer group becomes their space to explore and develop social skills in a safe environment among peers who have developed these skills and those who are continuing to develop these skills.

As treatment progresses through Phase Four, the chronically ill child will have begun to master developmentally appropriate socialization skills, which they will continuously practice and fine tune within the therapeutic peer group. This also is the place where the MEND therapist will help the child understand and respond to social cues appropriately and use peer positioning to help the encourage confidence in their new skills. As the child is transitioning out of treatment, they will then be
peer positioned with new incoming patients to be of service in the development of healthy social skills for the new patient as well as practice and strengthen their own healthy skills.

*Manage any Fails and Regression*

After phase four has been completed, the patient has now been prepared to graduate the MEND program. The patient will be evaluated by the MEND therapist to determine if the patient has met all treatment goals and has been fully integrated into age appropriate healthy development. As the patient graduates the MEND program, the MEND therapist will sit down with the family and patient individually to help reduce the chances of regression for the patient and the family system. The MEND therapist will help the family system manage any fails the child may encounter as they move forward. The MEND therapist will provide tips for any specific issues unique to that particular family system and patient.

In addition, family systems will be asked to continue to respond in a positive manner to behaviors that they want the patient to continue to demonstrate and to provide little emotional energy toward behaviors that they do not want to see. The patient will be encouraged to get their needs met in a healthy manner, which they will have practiced throughout the MEND model process. The patient will also be challenged to continue to get their needs met in a healthy manner even if the family system makes mistakes. If regression or fails are not managed appropriately, the family system and
patient will be given referrals to individual and family therapists to help with any regression at the end of treatment. The family systems and patient are also encouraged to check in with their MEND therapist periodically to inform them about the patient’s progress.

**Step Two: Identification and integration of supportive services**

**Step Two Goals:**

- Identify individual and systemic supportive services.

*Identify individual and systemic supportive services*

Each patient and family who seeks treatment in the MEND program brings with them very specific and often times unique needs. Some of these needs may require that additional services be put into place to best support the patient and their family when they leave the MEND program. The areas of focus follow the same ecological influences; Social, familial and academic mentioned at the beginning of this manual.

**Social**

To what levels the patient has integrated into a healthy, developmentally accurate pro-social activities, the therapist wants to insure that any roadblocks in maintaining or increasing these
activities are addressed and removed. This can mean continuing in the process of bringing social development within age appropriate levels through other identified outside group activities, or simply ensuring that new peer relationships are solidified, and that the family accept and support the relationships through encouragement, scheduling and transportation.

Family

Systemic needs in the family may require attention and attending to varying degrees once the family leaves the MEND program. It may be assessed by the MEND therapist that further clinical attention is not necessary, and that providing a structure and a schedule where family members can come together and check-in on how they are experiencing the system and its functioning to support its members is adequate. Providing this opportunity allows the process of voice regulation to continue and generalize. In addition, the implementation of “family check-ins” can reduce anxious processes by providing the knowledge that there will be a structured time and place where voices can be heard and issues addressed. Again, this may be an integrated process within the family system, or supported clinically, here is where the MEND therapist assesses continued support needs of the family.
Academic

Together with the patient, family, and sometimes the medical team, the MEND therapist reevaluates adjustments that were put into place to support the patient’s academic needs such as IEPs (Individual Education Plans) or 504 plans (Educational support plans for children with learning difficulties), modified schedules as well as altered physical expectations. Healthy integration or continued support is important, however for the MEND therapist there is a second agenda. In addition to participating as a member of the patient care team to ensure services meet the need of the patient, the MEND therapist will assess, and attempt to adjust when necessary, services to minimize processes that bring light to or reinforce differences in the patient from other “healthy” peers. For example, often times the schools response to the need for alternate physical education participation is to have the chronically ill child sit in the library while her classmates attend PE. It would be the MEND therapist’s perspective that this type of alternative support not only sends a strong message to the child about their limitations and being different, but does not accept the ability of the child to participate or contribute at any level. In addition the child is now separated from her peers and is missing the social aspects of that hour, further disconnecting her from a common social experience. Being absent from the social experience of her peers could eliminate her from social dialog about those experiences, driving a larger wedge in the already compromised social confidence of the
child. The MEND therapist may facilitate dialog about levels of participation that could benefit physical health and allow access to the social aspects of the hour. This may be as small as providing a supportive role to the physical education teacher, or acting as the assistant to the coach. The MEND therapist wants to support all of the systems involved in the patient’s life to have expectations for the child which push the limits and promote growth in each area of function, weather academic or physical.

**Step Three: Graduation**

**Step Three Goals**

- **Group Reflection:** Provide opportunity for the patient and family members to participate in supportive and reflective processes that emphasize their progress and newfound meanings.

Graduation is not just a time of celebration, but a last opportunity to participate in supportive and reflective processes with peers who have shared large portions of the child’s journey, or are accepting the experience, strength and hope of the graduate.
Multi-family Family Group Reflection

The graduate will present to the group a piece of work that was completed during a phase one language learning session. The graduate will then compare and contrast that work with the same assignment completed in the fourth phase of treatment. An example would be a self-portrait painted on the patient’s first day in MEND, and then held up in contrast would be another self-portrait completed within the last weeks of treatment. The graduate will then reflect for the group the journey that was experienced and which is reflected in the artwork. The MEND therapist then offers the group the opportunity to share how they have observed the patient’s journey as it pertains to the presentation of change within the presented intervention of the self-portrait. This has a powerful impact on the patient as their personal account of their journey toward health is reported by the group as accurate or congruent, thus reconfirming that the patient’s insides matched their outsides.

The last act of the graduation ceremony is for the graduating child to sit in the middle of the group and one by one listen to all of her peers and their family members express their personal experience and sentiment toward the graduate in a final well wishing. This is a time where the personal relational sentiments are shared as each member of the group participated and identified with the graduate’s process at different levels. The group members who have been with the graduate from almost day one express deep sentiment and share
how proud they are to have been involved in their journey, while newer members express gratitude for helping them integrate into the group as a mentor and source of strength and support.

Phase Four Milestones

By the end of Phase Four, families will have experienced solidified second order changes and projected this new level of systemic functioning onto potential future challenges at every ecological level. As an active member of the multidisciplinary team, the family will have gained insight and skills which will enable them to continue to activate and support growth in their child and family. In addition, the therapist will have worked with the patient and their family to design and promote positive reintegration into social and academic settings. If the MEND therapist has deemed it necessary, the family will have begun active involvement with additional supportive services. If the family system expresses the ability to support its own healthy functioning, then a plan for establishing “family check-ins” would be established.

Through the graduation process, the patient and their family participated in a ceremony which highlighted their unique journey amongst all current MEND participants. This graduation format allows all families to witness the experiences and successes of graduating families which provides benefits to all participants, whether they are new or seasoned
members of MEND. For the new families, it gives hope that the journey that is being recognized in the graduation ceremony is one that they too will experience. For the seasoned members, it provides the opportunity to express a deep, relational connection to the graduating peer and family members with whom they may have had significant involvement throughout their journey in MEND. The ceremony both influences and solidifies the treatment process for all members - new and old, patient or family. In this last act of the MEND program, the patient will have both shared and received experiences of strength and hope with everyone in their MEND family.
Introduction to Session/Topic:

In this session patients will be completing the 7 & 7 worksheet to begin the process of identifying patient’s expressions of emotions as healthy or destructive.

Skills Learned and Rationale:

Identification of emotions and the thoughts and behaviors associated with them

Lecture Points:

Share the stimulus response principle with the patients. Using examples explain the connection between thoughts, feelings and behaviors. Share how the decisions we make in response to our emotions can positively or negatively affect our physical and emotional health.

Discussion Points:

Prompt the group to identify and share an example of a time when a strong emotion was experienced. Process that experience as a group and identify the behaviors which were associated. Lastly, process the outcomes of those behaviors as healthy or destructive.

It is a good practice for the therapist to help facilitate the discussion through the lens of medical compliance. Help the patients to begin to
linking emotions, behaviors and their influence on adherence to healthy medication, diet and exercise practices.

Exercise & Practice:

Each patient is to complete as much of the 7&7 emotions worksheet as possible. If a patient cannot identify seven experienced emotions, offer some hurdle help. Many of the patients will be able to answer only four or five; that is expected and will allow space for family participation in the multifamily portion of the group.

Homework:

Give the patients a blank 7&7 worksheet and ask them to guide their family through the same process in the multifamily group using emotions of the family system to complete.

Multi-Family Group

Introduction to Session/Topic:

Identifying patient’s / families expressions of emotions as healthy or destructive.

Skills Learned and Rationale:

Participants learn that the family system influences the individual within it, and that the emotional state of that system is one of the tools the system uses to enforce rules and roles.
Lecture Points:

Individuals within a family system are influenced by that system. The rules by which the system expresses acceptance or non-acceptance of emotions and behaviors can influence individual stressors such as shame or guilt, and help to shape a child’s private logic and development.

Shame and guilt are experienced as stress within the body, and can cause changes in the patient’s cognitive functioning, immune system, and are also responsible for inflammatory processes within the body.

Discussion Points:

Behaviors purpose is to ensure that needs are met. When we experience a behavior that we don’t like or we are fearful of, we tend to want to extinguish the behavior without seeking to identify what need that behavior is attempting to meet. Needs can be met in both healthy and maladaptive destructive ways, which is how powerful a need is. The idea is to look at the need, not the behavior, and know that there are many correct answers. We can get the need met in other ways as well, ways that are not self-destructive, and don’t have shame and guilt attached to them.

Exercise & Practice:

After each patient shares and processes their 7&7 worksheet with the group, solicit help from the patient’s family to complete any sections which were left incomplete. Question the families to identify any emotions they see in their children which were not included in the worksheet.

Separate the families into working groups. Each family is given 30 min. to complete as much of the 7&7 emotions worksheet as possible. As the families work to identify family emotions and complete the worksheet, the therapist will walk amongst the groups offering clarification and hurdle help.
Homework:

There is no homework component to this session. Remind families that they are able to continue the process of positive discussion on what was learned and experienced in the group session. However if the discussion turns into a conflict or judgment, then the families are instructed to take note of the conflict for discussion in session, and are not to pursue the issue at home.
Dear....................,

Anger and Blame
I hate it when.....
It makes me furious when.....
I’m fed up with.....
I’m tired of ......
I resent......

Hurt and Sadness
It hurts me when.....
I feel sad when.....
I feel awful when.....
I feel hurt.....
I’m disappointed when.....

Fear and Insecurity
I’m afraid that.....
I feel scared that...
I am worried that....

Remorse and Responsibility
I’m sorry that....
I’m sorry for.....
Please forgive me for.....
I didn’t mean to.....

Intention and Wishes
I want....
I wish...
I hope...

Love, Forgiveness, Understanding, and Gratitude
I love you because....
Thank you for....
I’m proud of you for.....
I understand that....
I forgive you for....
I love it when....

Love....................
Body Image

Introduction to Session/Topic:
How I see myself / how others see me: body image

Skills Learned and Rationale:
Patients learn to integrate healthy practices of positive self-awareness while reducing the need to harshly judge their insides verses other people’s outsides.

Lecture Points:
- Body image
- Self esteem
- Positive awareness
- How I see myself
- How others see me

Discussion Points:
Many times children with chronic illnesses experience medications and procedures which leave both physical and emotional scars. Process with the patients the identified physical and emotional influences chronic illness has had on their bodies and feelings.
Exercise & Practice:

Patients will choose a partner of the same sex and have them draw the outline of their body as they lay flat on large construction paper. Patents can then choose to either draw, paint or cut from magazines, images to represent parts of themselves. Then the patient will create a division or bubbles to express their personal thoughts about each part, and how they believe others see or feel about the same part.

Homework:

Become more aware of accurate information when interpreting your responses to yourself, as well as others responses to you. Begin to question those automatic negative self-defeating beliefs.
Full integration requires connectedness within the cognitive, emotional and physical domains.

Our thoughts, feelings and behaviors are driven by the meanings we make within multiple ecological levels.

Disconnections in this integration may cause information to be distorted and inaccurate, which may lead to maladaptive behavioral responses.

**Interoception:** sense of one’s own physiological condition or internal state ... emotions, pain, thirst, hunger and body temperature, a Process of the Insula ... primarily physical.

**Introspection:** Sense of One’s own conscious thoughts and feelings ... primarily emotional.
Executive Functions

- foresight
- concentration
- abstract reasoning
- behavioral inhibition
- programming and planning goal-oriented behaviors
- executing a sequence of responses to avoid negative consequences or interactions
- generating alternative socially-adaptive behavioral responses
- learning from experience
- interpreting social cues
- problem solving
- verbal ability
- attention
Dorsal Vagal Regulation

F - Flexible
A - Adaptive
C - Coherent
E - Energized
S - Stable

Thoughts  <---  Feelings  <---  Behaviors
Fearful energy: The overt and covert overprotective behavior generated by the hypervigilant family system.

Excusing: Placing blame on the illness for unmet expectations.

Expectation incongruence: Holding different expectations for the chronically ill child and healthy siblings and peers.

Over burdening: Placing responsibility on the chronically ill child for systemic stressors and burdens.

Unbalancing: Unequal attention and energy provisions between healthy and ill children within the family system.

Constriction: The systemic influence of limiting potential growth.

Displacing: The placing of the chronically ill child with the special education population.

Accommodating: Accommodations for the limitations of the chronically ill.

Limiting: Allowing limited access to peer participation due to activities believed to be outside the range of the chronically ill.

Avoidant: Being avoided by peers and social groups due to fear and misunderstanding of the illness.

Expectation: The lowering of academic expectations for the chronically ill.

Comparing: The comparing of the healthy and the chronically ill.

Exclusion: Excluding the chronically ill child from regular social, academic and athletic activities.

Isolating: The ill child isolating from peers and social opportunities.

Acceptance: Being accepted into the general academic population.

Creating: The creation of a social network that excludes activities and peers which are active in activities believed to be outside the patient’s abilities.

Adopting: Adopting the negative imputes from society about the chronically ill as true.

Medical Illness: A pathological condition of a part, organ, or system of an organism resulting from various causes, such as infection, genetic defect, or environmental stress, and characterized by an identifiable group of signs or symptoms.

- Kidney Disease
- Cystic Fibrosis
- Organ Transplant
- Type I Diabetes
- Crohn’s Disease
- Celiac’s Disease
- Seizure Disorder
- Conversion Disorder

Child or Adolescent Meaning
Family Tree

Introduction to Session/Topic:

Family Tree

Skills Learned and Rationale:

Patients and their supporters participate in the identification of family history and strengths. Express in the process portion of the group how family strengths, rules and roles affect how we face adversity. Allow patients to begin identifying specific aspects of strengths witnessed and identified within their family.

Lecture Points:

- Body image
- Self esteem
- Positive awareness
- Empowerment
- Inner dependency

Discussion Points:

Many times children with chronic illnesses experience medications and procedures which leave both physical and emotional scars. How a child learns to cope with these stressors is in good part learned within their family system. Issues of Body image; Self-esteem, Positive awareness, Empowerment, and Inner dependencies are examples of areas in our lives which are influenced by our families.
Exercise & Practice:

Patients and their family will use the materials to add family members the child never knew or has little memory of. Family groups will fill in as many family members as can be remembered and identified. Alongside each identified family member, the patient will leave space (creatively as leaves or fruit...etc) to answer the three questions: #1. Identify a positive characteristic. #2. What role did he / she play? #3. How are you like this person?

The family will then synthesize all of the identified family strengths and report to the group these shared characteristics. In addition the patient and family will share how the identified family strengths will benefit in the current process of chronic illness.

Homework:

Post the completed family tree at home and place photos and memorabilia to more personalize the individuals represented.
Forethought

FORETHOUGHT: Thinking or planning out in advance ...

CONCENTRATION: The ability to focus attention ...

ABSTRACT REASONING: Thinking and problem solving outside the box ...

BEHAVIORAL INHIBITION: Impulse control ...

PROGRAMMING AND PLANNING GOAL-ORIENTED BEHAVIORS: Future thinking ...

EXECUTING A SEQUENCE OF RESPONSES TO AVOID NEGATIVE CONSEQUENCES OR INTERACTIONS: Cause and affect processing ...

GENERATING ALTERNATIVE SocialLY – ADAPTIVE BEHAVIORAL RESPONSES: Flexible responsiveness ...

LEARNING FROM EXPERIENCE: Temporal integration ...

INTERPRETING SOCIAL CUES: Accurately reading others and responding appropriately ...

VERBAL ABILITY: Language skills across multiple domains ...

ATTENTION: Focused energy ...
Somatic information from the body is experienced in the right side of the brain via the insula. The information is then passed through the corpus callosum where it can be labeled and language added to it. From here interpretation of sensations can be identified and processed. Through this process meaning can be formed, identified or altered.
Letter to 35 Year Old Self

Introduction to Session/Topic:

Letter to 35 year old self:

Skills Learned and Rationale:

Identification of childhood experiences coping with chronic illness, goal setting, and reframing of negative or stressful childhood events.

Discussion Points:

Many of the answers to life’s toughest questions are already inside us, but we feel weak or unsure of ourselves, and so we don’t trust our ability to make good choices. We also question our worthiness to have and experience all that a full life has to offer. Process some shared goals, and check-in on the patients belief systems about worthiness. Use Adler’s Striving for Superiority principles to gauge goal directed thoughts and behaviors.

Exercise & Practice:

Have each patient write a letter to their 35 year old self, expressing some of the struggles and pains experienced in childhood that causes them concern. Ensure that the letter includes many questions about how the identified stressors are played out in the time between now and when the patient turns 35.
Once the letter is complete, have the patient’s pair up with a peer and read their letters to each other.

Now the patients are to change roles with their 35 year old self and write an answer letter, answering all of the questions asked, and reporting on the outcomes of all the concerns.

Homework:

There is no homework assigned to this session.
Match Game Family

Introduction to Session/Topic:

Skills Learned and Rationale:
Patients are given the opportunity to answer 12 significant life questions. The questions cover five domains; goals, dreams, education, self-image and family functioning. Patients have the opportunity to tactfully integrate these domains into the cognitive process.

Lecture Points:
- Communication
- Goal and dream sharing
- Expectations of support
- Judgments
- Congruency

Discussion Points:
Process with the patients to be deliberate in their answers, identifying what has true and accurate meaning within the five domains. Prompt them to be bold and honest; express the value of accurate and assertive self-expression.

Exercise & Practice:
Each patient will take 12 pieces of paper and number them in the top right hand corner 1 – 12. Then the patient will read and answer question #1 on the reverse side of the paper marked #1. Instruct them
to write their answer in large bold words (large enough to be viewed from a distance of across the room). Once all 12 questions are answered in this manner, the patients will stack the answer sheets face down in front of them, displaying only the page number.

**MATCH GAME FAMILY**

1. What topic do you have difficulty talking about?
2. What do you consider your most special quality?
3. What is the best gift you’ve given someone?
4. What feeling is easy for you to share?
5. What would you like to be famous for?
6. What would you like to be doing ten years from now?
7. What would you most like to teach others?
8. If you could have one wish that would improve your family, what would you wish for?
9. What is something you would like to learn more about?
10. Who is a safe person you can talk to?
11. What special quality would you like to have?
12. What feeling is difficult for you to express?
Homework:

There is no homework for this session.

Multi-Family Group

Introduction to Session/Topic:

Skills Learned and Rationale:

Patient’s families are given the opportunity to match answers with the patients’ 12 significant life questions. The questions cover five domains; goals, dreams, education, self-image, and family functioning. Patients have the opportunity to tactfully integrate these domains into the cognitive process.

Lecture Points:

- Communication
- Goal and dream sharing
- Expectations of support
- Judgments
- Congruency

Discussion Points:

Process with the patients to be deliberate in their answers, identifying what has true and accurate meaning within the five domains. Prompt them to be bold and honest; express the value of accurate and assertive self-expression.
Exercise & Practice:

Each patient will be seated in a panel in the front of the room as their family sit in the audience. One by one the families get the opportunity to hear the question which was answered by the patient, and attempt to match that answer. A point is given to each correct match. At the 45 min mark the game goes into the bonus round where each correct answer gives that family another question until a wrong answer changes the player. Whoever has the most points at the end of the session wins.

Homework:

Take the question sheet, and the patients answer cards, home for process discussion of goals and their supporting role.
Meaning

- Fearful Energy
- Excusing
- Expectation
- Incongruence
- Overburdening
- Unbalancing
- Construction

- Limiting
- Avoidant
- Comparing
- Isolating
- Creating
- Adopting

- Displacing
- Accommodating
- Expectation
- Exclusion
- Acceptance

- Medical Illness

Family

Social

Medical

Academic
I Am Music

Introduction to Session/Topic:

I am music: Music Therapy

Skills Learned and Rationale:

Music is used as a therapeutic tool to promote reasoning ability, reading skills, feelings and response, personal fulfillment, language development, the promotion of communication, motor control and physical well-being, positive attitudes toward school, socializing and pleasurable experiences. Music also aids in integrative processes.

Lecture Points:

- Music captivates and maintains attention
- Music stimulates and utilizes many parts of the brain
- Music is easily adapted to, and can be reflective of, a person's abilities
- Music structures time in a way that we can understand ("that's the last verse - my exercise session is almost over!")
- Music provides a meaningful, enjoyable context for repetition
- Music provides a social context -- it sets up a safe, structured setting for verbal and nonverbal communication
- Music is an effective memory aid
- Music supports and encourages movement
Music taps into memories and emotions
Music and the silences within it provide nonverbal, immediate feedback
Music is success-oriented - people of all ability levels can participate

Discussion Points:

Process with family members their experience with music:

- What type of music do they enjoy and why
- How does music make them feel
- When do they use music in their own lives, and what is the outcome
- What role does music play in the family history

Exercise & Practice:

Participate in the viewing and process of others musical creation. Identify themes and underlying storylines within the effort. Share your emotional impressions of the music experienced.

Homework:

Find a family music genre: Explore, as a family, different types of music with the goal of finding a sound that the entire family can agree is enjoyable to listen to. This will require the nonjudgmental listening to of each family member’s musical likes. Make efforts to find the similarities in sound or theme of the different music genres. Create a play list of agreed upon music, and listen to that music when together as a common interest.
We Are Music

The music I hear ...

Introduction to Session/Topic:

The music I hear: Music therapy

Skills Learned and Rationale:

Patients and their families learn to use music to relax, reduce stress, manage pain, and regulate body functions such as heart rate, breathing. Music can also be used to arouse, energize, and reassure.

Lecture Points:

Music can help us access ideas and thoughts that need to be examined and discussed, while also bringing to the surface feelings that need to be expressed and shared.

Discussion Points:

Music listening can be used to stimulate images, fantasies, associations, and memories, all of which contribute immeasurably to the process. Listening to music can facilitate structured reminiscence or a review of their lives.

Exercise & Practice:
The patient and their family takes in and reacts to live or recorded music. The listening experience may focus on physical, emotional, intellectual, aesthetic, or spiritual aspects of the music, and the client may respond through activities such as: relaxation or meditation, structured or free movement, perceptual tasks, free-association, storytelling, imaging, reminiscing, drawing, and so forth. The music used for such experiences may be live or recorded improvisations, performances or compositions by the client or therapist, or commercial recordings of music literature in various styles (e.g., classical, popular, rock, jazz, country, spiritual, new age).

**Homework:**

Find a family music genre: Explore, as a family, different types of music with the goal of finding a sound that the entire family can agree is enjoyable to listen to. This will require the nonjudgmental listening to of each family member’s musical likes. Make efforts to find the similarities in sound or theme of the different music genres. Create a play list of agreed upon music, and listen to that music when together as a common interest.
Self - Portrait …

Introduction to Session/Topic:

Patients now choose a medium for creating their self-portrait; watercolors, acrylic, pastels, color pencils, markers, etc... patients are given the time remaining until 5:30 to complete task.

Skills Learned and Rationale:

Patients are given the opportunity to use tactile efforts integrating both right and left hemispheres of the brain to synthesize self-perception.

Lecture Points:

Speak to the group about how the personal image of ourselves has been shaped by all of our life experiences and the culture we live in. Our experience living with an illness is part of our lives, and the meaning we assign to it was given to us by our culture. Ask some open ended questions about the meaning of chronic illness that has been given to them. Where did they receive information about the meaning illness has played in their lives, is that information accurate, and how does it shape their self-image?

Discussion Points:

After the patients have begun their task, inform them that this interpretation is an integrated process and that the best outcomes will happen when they just experience the flow of the work without thinking too much about it or attempting to place perfectionist expectations on the outcome.
Please give minimal instruction before work has begun; we do this for two reasons. 1st it will be the nature of many patients to over think or simply pre-create the task before starting. This interferes with the 2\textsuperscript{nd} reason which is that you want the flow process to take place during the tactile experience, this creates a significantly less restricted integration of accurate expressive processes.

-  

**Exercise & Practice:**

Patients are cued to create a liking of themselves which represents how they are perceived in their minds eye. NO other instructions are given as the patients need the minimal structure so as not to obscure their honest creative focus.

The role of the therapist is to lend positive encouragement to patients as he /she moves around the room. The therapist may comment on observation without making interpretations. Socratic questioning may be used to help bring patients tactile efforts into linguistic domains, integrating new and accurate information.

**Homework:**

Instruct the patients to take their self-portrait home and hang it in a place where it will be seen on a regular basis. Instruct the patients to make regular interpretations as they experience the image, and take notice of how accurate or inaccurate your perception of the image is. What about the image would they like to change? How could the image be more accurate? Make it a point to notice the changes of perception through treatment, and use those identified changes and topics of your check-in free writes.
Introduction to Session/Topic:

Multifamily session is used to process the identification and integration of the patients self-image as represented by the self-portrait activity.

Skills Learned and Rationale:

Patients and families learn to communicate accurate information in an accepting nonjudgmental way.

Lecture Points:

Now that the family has joined their child for the last hour of the treatment day, go over again how the personal image of ourselves has been shaped by all of our life experiences and the culture we live in. Our experience living with an illness is part of our lives, and the meaning we assign to it was given to us by our culture.

Discussion Points:

Ask some open ended questions about the meaning of chronic illness that has been given to them. Prompt the families to think about their belief systems and how these beliefs were passed down and integrated by their children.

Exercise & Practice:

One by one have the patients share their self-portrait and process the integration of their identified meaning. Ask peers and family members what they see in the work. Challenge any judgment or cognitive distortion. Facilitate healthy emotional reciprocity between family members by removing systemic barriers to communication.

Homework:
Explain to the families what homework was given to the patient;

Instruct the patients to take their self-portrait home and hang it in a place where it will be seen on a regular basis. Instruct the patients to make regular interpretations as they experience the image, and take notice of how accurate or inaccurate your perception of the image is. What about the image would they like to change
Stone Exercise

Introduction to Session/Topic:

Stone exercise: the burdens that we carry.

Skills Learned and Rationale:

Participants will be able to identify the burdens they carry and at what expense.

Lecture Points:

The longer we hold our burdens the heavier they become. Requiring us to filter all our personal, familial, and social relationships through the pain and weight of the burdens we carry. Protecting the lies of our secrets and the pain of our burdens comes first in all aspects of our being. This disallows true honesty and intimacy to be experienced with ourselves and others.

Discussion Points:

The concept of the Stone exercise is to demonstrate how the burdens we carry influence our emotional and physical health. The burdens we carry are represented by the Stones. The stones are marked with names; resentment, anger, shame, abandonment, and a few are blank, indicating a secret held by the patient. You may also notice resentment stones of different sizes which correlates with the size and weight of the resentment. Included is a vest to hold the identified stones or a bag in which to carry them. The main difference between the vest and the bag is that since the bag has two handles, it allows the therapist to demonstrate codependency.
**Exercise & Practice:**

**Individual:** place the stones face up in a pile in the center of the room. Prompt the patient to choose as many stones as they identify with. You may find it necessary to explain to the patient and the group the definition of resentment. Once the patient has selected all of the stones which hold meaning for them, direct them to put on the vest. As the therapist places stones into the vest one by one, he or she explains to the group how the weight of the burdens we carry holds us down and influences how we interact with our family, peers and environments.

Now you can show the patient and the group how to gain relief from their burdens. Ask the parent or family member of this patient to stand directly in front of the patient. Then have the patient choose a stone from the vest and one by one express the meaning of the burden the stone represents. As the patient and the family process the burden and make amends for it, the parent or family member can take the stone from the patient and place it back in the bag or on the floor. As this process continues, make correlations for the group regarding the decreasing weight of the vest and the weight of the burden carried. When the vest is empty, process with the patient and the group how the weight of the burden no longer serves to interfere with the patients interpersonal or extra-personal experience.

**Group:** prompt half a dozen or so individuals from the group to take a rock from the center of the room and then return to their seats. Have them remain standing and ask them to express one at a time the significance of the stone they hold. Once they have shared, ask them to hold the rock out in front of them while you continue to address the other group members. Once finished begin your explanation of the concept of burdens.

While you are speaking, keep an eye on those holding stones and address them every time you notice the person getting tired, lowering the stone, or dropping there arm. This is your opportunity to reinforce how that the longer we hold our burdens the more pain and fatigue they cause. As time goes on, more and more participants will struggle,
you can then question them as to how present they are in the room. Can they clearly be present to what is going on around them? As the struggle they are experiencing gains in intensity they will become less and less present in the room. Help them make correlations between this and how it is the same with all other aspects of their life, such as relationships, coping with stress, and their physical health. Now, take them through the process of releasing these burdens and feeling less distracted and their experience of more clarity.

**Homework:**

Processes identified burdens, and with permission, support each other in their efforts to release the stone they carry. Express to the families how easy it can be for the stone of someone’s burden to be used though back at them when conflict ensues. Share how sacred the trust of sharing our deepest burdens is.
Interoception Music

Introduction to Session/Topic:

The music I hear: Music therapy

Skills Learned and Rationale:

Patient’s learn to use music to relax, reduce stress, manage pain, and regulate body functions such as heart rate, breathing. Music can also be used to arouse, energize, and reassure.

Lecture Points:

Music can help us accesses ideas and thoughts that need to be examined and discussed, while also bringing to the surface feelings that need to be expressed and shared.

Discussion Points:

Music listening can be used to stimulate images, fantasies, associations, and memories, all of which contribute immeasurably to the process. Listening to music can facilitate structured reminiscence or a review of their lives.

Exercise & Practice:
The patient takes in and reacts to live or recorded music. The listening experience may focus on physical, emotional, intellectual, aesthetic, or spiritual aspects of the music, and the client may respond through activities such as: relaxation or meditation, structured or free movement, perceptual tasks, free-association, story-telling, imaging, reminiscing, drawing, and so forth. The music used for such experiences may be live or recorded improvisations, performances or compositions by the client or therapist, or commercial recordings of music literature in various styles (e.g., classical, popular, rock, jazz, country, spiritual, new age).

**Homework:**

Identify and bring to group music which connects with you, and holds significant emotional properties to either soothe, relax, calm or energize you. This can be in the form of a CD, DVD or live singing or instrumental piece performed by you.
### The Sympathetic and Parasympathetic Nervous Systems

<table>
<thead>
<tr>
<th></th>
<th>Sympathetic System</th>
<th>Parasympathetic System</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Function</strong></td>
<td>To defend the body against attack</td>
<td>Healing, regeneration and nourishing the body</td>
</tr>
<tr>
<td><strong>Overall Effect</strong></td>
<td>Catabolic (breaks down the body)</td>
<td>Anabolic (builds up the body)</td>
</tr>
<tr>
<td><strong>Organs and Glands It Activates</strong></td>
<td>The brain, muscles, the insulin pancreas, and the thyroid and adrenal glands</td>
<td>The liver, kidneys, enzyme pancreas, spleen, stomach, small intestines and colon</td>
</tr>
<tr>
<td><strong>Hormones and Substances It Increases</strong></td>
<td>Insulin, cortisol and the thyroid hormones</td>
<td>Parathyroid hormone, pancreatic enzymes, bile and other digestive enzymes</td>
</tr>
<tr>
<td><strong>Body Functions It Activates</strong></td>
<td>Raises blood pressure and blood sugar, and increases heat production</td>
<td>Activates digestion, elimination and the immune system</td>
</tr>
<tr>
<td><strong>Psychological Qualities</strong></td>
<td>Fear, guilt, sadness, anger, willfulness, and aggressiveness.</td>
<td>Calmness, contentment and relaxation</td>
</tr>
<tr>
<td><strong>Factors That Activate This System</strong></td>
<td>Stress, fears, anger, worry, excessive thinking and too much exercise</td>
<td>Rest, sleep, meditation, relaxation therapies and feelings of being loved</td>
</tr>
</tbody>
</table>
Thoughts → Feelings → Behaviors

Thoughts:
- Meanings
- Context
- Beliefs
- Paradigms
- Archetypes
- Schemas

Feelings:
- Comfortable
- Uncomfortable
- Regulated
- Deregulated

Behaviors:
- Coping
- Adaptive
- Maladaptive

Behaviors are designed to support comfortable regulated emotions, or change emotions which are uncomfortable or deregulated.

Responses to this behavior from all ecological levels coauthor or validate the original thoughts or meaning as accurate.
Introduction to Session/Topic:

WANT ADD: patients will complete a want add for a new organ (Kidney, Heart, healthy pancreas, healthy blood etc...).

Skills Learned and Rationale:

Identification of the patient’s strengths and the positive healthy aspects of their body.

Lecture Points:

How can:

- Strength influence weakness
- Healthy influence sick
- happiness influence sadness
- Kindness influence meanness
- Love influence hate
- Diet influence healing energy
- Medication influence illness

Discussion Points:

While there are some struggles we face with illness, there are some very positive and healthy aspects of our bodies. How can we use those positive healthy parts of us to influence our experience with illness? Do we think of ourselves as sick, or as creative; loving, healthy, caring, strong, intelligent…..but also have an illness?
How can those identified strengths and healthiness influence the part of us that is experiencing an illness?

**Exercise & Practice:**

Each patient will identify and list their positive strengths and healthy physical attributes. Patients will then choose to paint, draw or cut from magazines, images which represent for them their identified strengths and attributes. Patients will then create an advertisement directed at soliciting a healthy organ or condition. Patients may use any means desired to get their message across; music, slide show, puppets, billboards etc...

**Multi-Family Group**

**Introduction to Session/Topic:**

WANT ADD: patients will complete a want add for a new organ (Kidney, Heart, healthy pancreas, healthy blood etc...).

**Skills Learned and Rationale:**

Identification of the patient’s strengths and the positive healthy aspects of their body.

**Lecture Points:**

How can:
• Strength influence weakness
• Healthy influence sick
• happiness influence sadness
• Kindness influence meanness
• Love influence hate
• Diet influence healing energy
• Medication influence illness

Discussion Points:

While there are some struggles we face with illness, there are some very positive and healthy aspects of our bodies. How can we use those positive healthy parts of us to influence our experience with illness? Do we think of ourselves as sick, or as creative; loving, healthy, caring, strong, intelligent.....but also have an illness?

How can those identified strengths and healthiness influence the part of us that is experiencing an illness?

Exercise & Practice:

Patients take turns sharing / performing their advertisement assignment.

The group supports the patient’s efforts and shares feedback on the patient’s discovery of strengths. The families then can also process other ways in which the patient’s strengths can influence illness. Families can then process their collective strengths as a supporting role for the patient.
Coauthored Stories

Introduction to Session/Topic:

Coauthored Stories ...

Coauthored Stories is a projective exercise where participants carry-on the stories of others, and experience others participating in the fulfillment of their own narratives.

Peer group:

For this exercise the facilitator will need 4ft long pieces of white construction paper for each patient, painters tape and colored markers. Instruct the participants to draw a character of their choosing in the top left quadrant filling about a square foot or so of the paper. When the participants complete the creation of a character, instruct them to identify a struggle they are experiencing. Using their character as an externalization, instruct the participant to write the first two sentences of the characters story.

Multi-Family group:

Hang each of the story sheets on the walls around the room. Offer each or the participants and their family members to choose a colored marker, ensuring that there are multiple colors representing many coauthors. Then instruct the participants to “work the room” reading each story as it progresses, and then add a line or two, remembering that every story is to have a beginning, a middle and an end.
Once every participant has contributed to each story, have the original author stand next to their story and one by one introduce their character read aloud to the group their completed story. Process with the storyteller how they experience the development of their story and its outcome. Ask questions about how they connect to what others have contributed to their story. Process with the other group members and family how they experience the stories accuracies when representing the strengths in the story.

Skills Learned and Rationale:

The exercise gives the patient the opportunity to identify with the accuracies and inaccuracies, strengths and weaknesses of their perception of a problem. It allows the child to invite others into their individual narratives, allowing others to share alternative constructs and possibilities.

Discussion Points:

As the session comes to a close, share with the group how this exercise is a good representation of how opening ourselves to the support of others can give us information and opportunities which could of great benefit. Explain that at times when we are having personal struggles we can get myopic and unable to see clearly all of the resources around us. Take a minute to reflect on the “burdens talk” and remind the participants that taking on personal challenges alone can be a difficult struggle, and for the supporting cast in our lives a feeling of helplessness when there are not allowed join in the effort.

Homework:

Encourage the participants to take their coauthored stories home with them and hang them up where they can be seen. Ask them to continue
to reflect on the stories and the possibilities they represent. Does seeing their story crafted with the impute of others alter their narratives.