



PUTTING ILLNESS IN ITS PLACE:

Multidisciplinary Care in the National Jewish Pediatric Day Program

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When chronically ill children fail standard outpatient treatment, are there any therapeutic alternatives? National Jewish has developed an innovative, medical treatment program over the past several years to meet the needs of these youngsters with poorly-controlled asthma and other chronic illnesses. These children are managed in an intensive day treatment program that simultaneously addresses their medical disorder, psychologic distress, and family situation.

The National Jewish Day Program employs a team approach to chronic illness treatment that involves parents as well as the pediatric patient. The program's collaborative design includes psychosocial evaluation and interven-

tion in concert with medical assessment and treatment. This approach enables treatment of the "whole" child in the context of the family.

The Day Program gives families a unique opportunity that combines time and structure to focus on understanding and managing their child's illness. This program can achieve improvements in the difficult-to-control pediatric patient that are often impossible in the outpatient setting, while significantly reducing the cost of care compared to an inpatient stay.

Who participates?

National Jewish's Day Program is designed to accommodate children with a variety of chronic diseases, including asthma and other pulmonary disorders, atopic dermatitis, food allergies, bronchopulmonary dysplasia, systemic lupus erythematosus, juvenile rheumatoid arthritis, vocal cord dysfunction, failure to thrive, and other immune and allergic diseases.

Criteria for admission are well defined. In general, the program is designed for families with children who have failed standard, outpatient treatment. Treatment failure can be due to a variety of factors including illness severity, noncompliance, lack of diagnostic clarity, or family problems that interfere with outpatient management. Many patients have already received extensive outpatient workups that have failed to identify why their illness was out

of control. In many cases, emotional and family stress complicate the issues of medical compliance and daily disease management. This is important, as results from several studies suggest that unresolved psychosocial issues may place a child with a chronic illness at risk of

having an uncontrolled illness that becomes life-threatening. The psychosocial issues may be subtle, such as a difficulty by the parents or child in accepting the chronic nature of the disease or school problems that are secondary to the illness, or obvious such as conflicts between parents and child on treatment compliance. In some cases there may be a more severe psychosocial problem, such as anxiety, depression, or oppositional behavior, that can be addressed during the Day Program evaluation.

Family involvement is central to the Day Program. Parents usually serve as the illness managers, but the child must learn the skills he will eventually need to manage the disease on his own. Learning how to define roles and responsibilities for parents and children is central to good illness management. Having a child with a chronic illness is an enormous stress for all family members. Families that function best under these circumstances are those that have learned how

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UPDATE

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maximize their coping and competency skills, and this is a major task during the family's stay.

Treatment goals

Throughout the stay, a primary goal is to provide state of the art medical assessment and treatment of chronic illness by a team of experts in allergy, pulmonology, and immunology. The program is also designed to help families assess how the illness has affected them and to "put the illness in its place" in order for the child and family to lead a normal life. Other goals depend on the age of the child. For younger children, a primary aim is to have parents learn how to become optimal "illness managers."

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For older children and adolescents the aim is to have the patient learn the necessary skills to take increasing responsibility for care of their own illness. We encourage parents to hand over tasks to the child over time as appropriate for the child's stage of development. The staff provides guidance in

this by a knowledgeable assessment of the developmental level and emotional readiness of each patient who enters the program. In general, the program enrolls patients from infancy to 18 years old, although young adults up to age 20 can be accommodated if appropriate.

Another central goal is to provide personalized education about all aspects of the disease and its management, and to develop and implement a plan for managing the illness at home. Education is a cornerstone of our program. Children and parents must learn to understand their chronic illness in order to take control of the illness instead of allowing it to take control of them. They must recognize that there is no magic cure for the child's disease, but that there are ways to minimize its impact. The best way for them to cope is to become knowledgeable about the disease, and learn how to manage it effectively. Having a disease under control means that the child will miss fewer days from school, have fewer emergency room visits, and require less treatment with corticosteroids, thereby improving quality of life for the entire family.

Families who come to the day program often feel isolated in their home community, and believe that no one else understands their experience. The

opportunity to meet other families with similar situations is therapeutic, and is another positive outcome from the program. The affected children, whose lives are often severely limited by their illness, can meet other children who face the same difficulties. Many families report that the Day Program provided their child with the first opportunity to meet and make friends with other children who were like themselves, in a setting that removed the fear of stigma or ridicule.

Program structure

The National Jewish Day Program was initiated in July, 1995, when we shifted our focus from long-term inpatient treatment to more economical outpatient models. The Day Program unit is co-directed by a pediatric allergist and a child psychiatrist. This unique administrative structure is reflected in patient care in that an attending pediatric allergist and child psychiatrist co-manage the care of each patient. Other members of the treatment and education team include psychosocial professionals, art therapists, rehabilitation therapists, speech therapists, and a pediatric dietitian as needed.

On referral to National Jewish, a child and her family undergo an initial telephone screening by our Lung Line® and Physician Line® staff that identifies the individual needs of the patient and family. A decision is then made in tandem with the home physician and family about which National Jewish program is best suited to the patient's needs. Families and children who do not seem to need intensive observation and milieu-based care may participate in the National Jewish outpatient clinic. Patients who are experiencing an exacerbation of disease on arrival may need treatment in our overnight facility until their disease stabilizes and they are ready for a less intensive level of care and can participate in the evaluation.

Once at National Jewish, the patient and parents meet with the medical, nursing, and psychosocial team members, who conduct simultaneous evaluations during the first day or two after admission. An initial psychosocial evaluation is completed, followed by ongoing individual and family psychotherapy as needed. Treatment decisions are made in consultation with all members of the treatment team. Clinical review meetings are held every few days for each child in the program, and a larger treatment team conference occurs weekly to consolidate input from all of the professionals involved in a child's care and to develop recommendations for home care following discharge.

The child's portion of the Day Program involves

self-assessment, treatment, and education. Parents also participate in a variety of educational programs, both on their own and with their children. Parents of older children may be asked to leave their children during a portion of every day. The message we want to convey is that they can safely step back from their adolescent and pursue other activities on their own. For many parents this may be the first step they have taken in years toward reestablishing their own lives.

The balance of the program includes group therapy, rehabilitation therapy, and school. Children in the day program also enroll in an on-site school that has a regular enrollment of more than 100 children with chronic illness. Returning to school is important, as many of our patients have missed significant amounts of schooling due to their illness.

A major advantage of the Day Program is that the staff can observe patients throughout the day for several days in succession. This enables the staff to monitor medication effects, techniques of self-care, adherence to treatment regimens, family interactions, and child behavior. Our highly trained staff works intensively with the patient and family to uncover aspects of the disease situation that cannot be discerned during brief outpatient encounters. Team members are encouraged to report their observations and make recommendations to enhance care by each discipline.

A typical course of treatment in the Day Program lasts two to three weeks, but each stay is tailored to the needs of the patient. Children and parents are at National Jewish from 8 AM to 5 PM, Monday through Friday and half day on Saturday. During the evenings and on Sundays, families are on their own, which allows us to assess their integration of medical recommendations into their regular routine. When they return the next morning, the family is debriefed by the nursing staff, who will immediately reinforce or teach ways to improve the medical regimen. This daily feedback system allows the attending physician to adjust medications and lets the psychosocial clinicians review behavioral problems that interfere with management.

During the Day Program, contact is maintained with the referring physician and any family members who did not travel to Denver. As the time for discharge approaches, team members at National Jewish contact their key counterparts at the patient's home. In addition, videotapes are sent home with the family to help educate family members, teachers, and day-care providers. Extension of the treatment program from National Jewish to the home setting is crucial for sustained success.

Case Presentation

Tiffany is a thirteen year old girl with severe asthma and atopic dermatitis. She came to National Jewish with her mother from a suburb of New York, where they had been unable to succeed in managing Tiffany's lifelong, chronic illness. Tiffany had missed 30 days of school in the previous year, and both her family life and her peer friendships had suffered due to the restrictions placed on her by her uncontrolled illness. Her mother complained that she bore the burden of her daughter's illness, and that she was tired of hearing doctors tell her that she needed to do something about Tiffany not taking her medication or doing her skin care properly.

Tiffany was overweight, and her body showed side effects of chronic steroids. She was angry and depressed, and her family complained about her frequent temper tantrums about having to take her medicine or do her skin treatments. Tiffany's home physician and the family shared the same goals for their stay, including tapering her off chronic steroids, increasing her activity levels, reengaging her in school, and addressing her noncompliance and apparent depression.

At admission, the family met with the treatment team, and the home physician was contacted. Goals were agreed on, and both Tiffany and her mother began the program with clear expectations about what they were to accomplish. During the first three days, Tiffany underwent detailed pulmonary testing and consultation with the dermatology team. She met frequently with the nursing staff, and her medical compliance and technique were assessed. It was determined that Tiffany's knowledge about her condition was poor, and her compliance and technique were also suboptimal. Her mother's knowledge was good, but significant parent-child conflict was observed when the pair were together, particularly during medication times. The psychologist working with the family thought that Tiffany did show evidence of depression, and family interviews (including her father by long-distance telephone) revealed significant anger and frustration in all family members.

After the initial evaluation, Tiffany was immersed in the education and rehabilitation programs for both asthma and atopic dermatitis. She participated in an intensive hydrotherapy technique to treat her atopic dermatitis, and was rewarded with significant

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improvement within four days. She attended school, where an evaluation was done indicating that although she was very bright, she was not achieving her full potential in school. In psychotherapy, she and her mother discussed the resentment that had built up over the years about responsibilities in the family, and Tiffany agreed to take on more responsibility for her self-care in return for privileges. Over the course of the three week stay, a corticosteroid taper was begun that was to be continued at home, with specific instructions provided to the home physician. Follow-up contacts after discharge revealed that Tiffany was doing well, and had returned to school full time.

Measuring success

We are in the process of collecting and analyzing data on the outcomes of our program since it began almost a year ago, and at this time the conclusions are preliminary. As of February, 1996, 130 families have participated. Our data suggest that families experience a significant increase in their ratings of perceived competence in managing the illness over the course of hospitalization, including the ability to detect early warning signs of an exacerbation, knowledge of what to do in a crisis, and how to manage the daily regimen. An increase in perceived competence is critical, because a family's ability to manage their child's illness on a day-to-day basis will determine their ability to decrease the unnecessary medical utilization that can occur when a family feels helpless and inadequately trained to handle routine health care tasks at home.

Reimbursement

Third party payers have begun to recognize the value of day treatment. The program at National Jewish costs about 40% less than similar programs that involve an inpatient setting. Although some insurance companies have no mechanism for paying for medical and behavioral health treatment rendered in this manner, our case managers work closely with third party payers and insurance case managers to facilitate the reimbursement process. Case managers are often pleased to discover our Day Program option for treating complex patients who have previously accumulated enormous medical charges without demonstrable improvements in their medical utilization or quality of life.

Children and families who come to National

Jewish often arrive angry, frustrated, confused, and fearful, and these feelings are often shared by their care providers at home. Their distress stems from a combination of medical illness, emotional turmoil, and adverse life experiences. The National Jewish Day Program places these patients and their families in a healing environment. The process is designed so that health care professionals are able to listen carefully to families about what they have experienced and incorporate them as partners in tackling the problems. Children with chronic, intractable illness that has not responded to care at home may benefit dramatically from the intensive observation and assessment provided by our multidisciplinary, collaborative approach.

References

1. Gavin LA, Roesler TA, Brenner AM. *Day treatment in pediatric patients with medical and psychiatric needs*. In Press. *Continuum: Developments in Ambulatory Mental Health Care*.
2. Roesler TA, Gavin LA, Brenner AM. *Collaborative care in a tertiary care setting*. *Family Systems Medicine*, 1996;13:313-8.
3. Wamboldt FS, Wamboldt MZ, Gavin LA, Roesler TA, Brugman SM. *Parental criticism and treatment outcome in adolescents hospitalized for severe chronic asthma*. *J Psychosomatic Research*, 1995;39:995-1005.
4. Ooms T, Rolland JS, Mintz SG, Doppelt LS. *Family Systems Medicine*, 1995;13:299-31

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Specific Patient Elements by Disease Category

Pulmonary Patient Condition Elements

Mandatory: 1 and 2

1. The patient has demonstrated instability and variability of medical status, as evidenced by **at least one** of the following:

- More than one ICU admission in the past year
- Two or more hospitalizations longer than 48 hours in last 12 months
- Number of ER visits in last year >4
- FEV1 or Peak Flows 75% predicted or less >3 of the last 12 months
- Diurnal variability in FEV1's and Peak Flows of 30% or more
- Any intubations in last year
- Recurrent nighttime awakening with respiratory symptoms
- Sleep disorder, especially with asthma or hypoxic episodes
- Hypoxic seizures
- Oxygen desaturation at night or with exercise
- Metered dose inhaler abuse

2. The patient has been refractory to outpatient management in the home community.

- Increased frequency of medical intervention over the past year without improvement
- Assessed on an outpatient basis with the determination that the patient's condition precludes safe management at a less intensive level of care.

One of the following must be met in addition to 1 and 2:

3. The patient has an intensive medication regimen with multiple medications or daily treatments required for illness control.

- Bursts of high dose steroids >8 over last year (every 6 weeks or more)
- Maintenance oral steroid dose >0.5 mg/kg/day, e.g., >10 mg qod for infant to toddler, >20 mg qod for middle age child, 30 mg qod for adolescent; Any daily dose of oral steroid
- Maintenance inhaled steroid dose >2 mg/day
- Failure of high dose oral and inhaled steroid regimen, and consideration for alternative therapy (IVIg, Methotrexate, TAO)
- Adverse drug reactions to medications needed for disease control
- Daily or alternate day Troleandomycin/Medrol

4. The patient is steroid dependent and necessitates evaluation of steroid requirement and tapering of steroid therapy.

- Requires evaluation of steroid requirement
- Requires rapid steroid taper, necessitating close observation
- Refractory to steroid therapy, requiring consideration of new treatment approach

5. The patient has severe steroid side effects requiring intensive physical rehabilitation and concomitant reduction of steroid dosage.

- Obesity
- Cataracts
- Bone demineralization
- Cushingoid features
- Diabetes
- Adrenal suppression
- Other

6. The patient presents with other diseases complicating medical management, such as diabetes, seizure disorder, GE Reflux, hypertension, cardiac disease, or adverse reactions to medications needed for disease control.

7. Psychosocial Issues: The patient presents with psychosocial issues such as noncompliance and behavioral maladjustment that affect physical condition, complicate treatment, inhibit outpatient success and place patient at risk for morbidity and mortality.

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