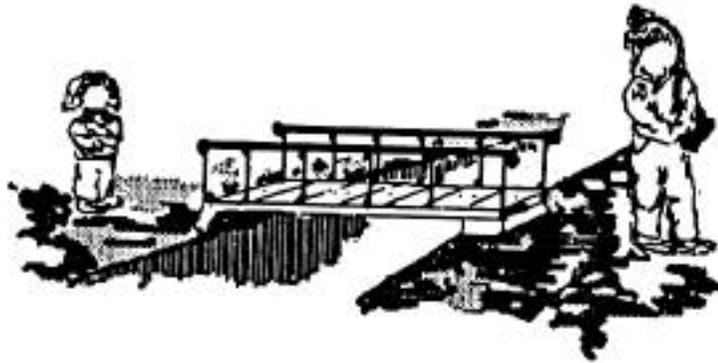# CROSSINGS:
# A MANUAL FOR TRANSITION OF CHRONICALLY ILL YOUTH TO ADULT HEALTH CARE

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# INTRODUCTION

In ths past many chronic pediatric conditions have resulted in early mortality and thus patients have not required health care as adults. As a result of improving technology, many patients with chronic pediatric conditions are now living well into adulthood. The adult health care system, however, has in the past not bsen ready and, in many instances, vvilling to take on these patients because of the lack ot knowledge of the disease. Patients themselves have been reluctant to move into the adult health care model because they have had to give up the team approach and the multiplicity of services that have typified pediatric care. Nonetheless, staying in the pediatric setting robs them of needed independence, in many instances, and appropriate sub-specialty care by those familiar with adult medical issues.

This manual is intended as a guide for health professionals to establish a new health care delivery system for transitioning adolescents with chronic illness to adult health care. The manual is based on the experience of a cystic fibrosis team in a hospital for children and a department ot internal medicine, section on pulmonary disease (in collaboration with other appropriate hospital departments) in developing a model of care lhat fostered the successful transfer of patients from one program to the other. While the experience was with patients with cystic fibrosis, the process for developing the model and tho model itself has broad application to a variety of chronic diseases,

Historically, there have been a number of issues that have made it difficult to develop a successful delivery system model that leads to a smooth transition to adult health care for chronically ill adolescents. These patients have often had difficulty finding an adult health care setting where professionals are knowledgeable about their pediatric conditions and where the model of care is one that provides the level ot support they have received in pediatric settings. Within both the pediatric and adult care setting, there are a number of financial complications that may make it difficult for pediatricians to transfer their patients or for adult care givers to want to assume their care. Patients themselves may find that there are differing financial implications tor them, depending on the setting of care. Finally there has been a need for information about how to help patients and their families successfully negotiate the transition from childhood to adulthood within the health care system. Health care professionals wishing to embark on the process of molding the health care system to support successful transition need to consider all of these issues as they work towards that goal. This manual will help you systematically address these issues as you plan and execute your own approach to amending the health care system to support the smooth movement of adolescent patients into adulthood.

The care of patients with chronic pediatric conditions that persist into adulthood is generally highly specialized and complex. Most receive care in special centers or programs located in tertiary care facilities for these conditions. Often primary care for total health needs Is provided in these centers rather than within the patient's own community. This approach can be a problem for both the adolescent and the adult patient. Typically the movement to adult care within these specialized settings has not proceeded smoothly because of the high degree of specialization within each section of the tertiary setting. This manual focuses on addressing the issues within those specialized settings, although always with an eye to the continued need for communication between the primary caregivers in the community and professionals in the tertiary center. The need for developing adequate primary care is an important one but beyond the scope of this manual

There are several assumptions underlying the development of this manual and the project on which it is based. Understanding these assumptions and Considering whether you can accept and support this view of care is undoubtedly important to your successful use of the manual as a road map. Successful transition requires the strong belief in certain basic premises. Our ten basic beliefs are:

1. **Many chronic, congenital, genetic handicaps or diseases can no longer be considered exclusively "childhood diseases."**

2. **Adolescents and adults with chronic "pediatric diseases are entitled to achieve independence and self-sufficiency.**

3. **Because of its intrinsic nature and the milieu in which its activities take place, the pediatric care team is not entirely successful In achieving Independence for adult patients.**

4. **The team approach Is an essential part of the care of chronically ill patients regardless of their age.**

5. **Patients, particularly adults (and older adolescents), can adapt to a new health care system In a positive manner provided this system fulfills thelr needs.**

6. **The adult health care system and adult caregivers are perfectly able to provide quality care to these adolescents/young adults with appropriate training in the area In question.**

7. **TransitIon, transfer and change should be offered as an option and not Imposed upon patients.**

8. **The leaders and the members of the adult and pediatric team must believe in the concept of transition, strive for excellence In patient care, and project a positive image of transition to patients and their families.**

9. **The members of the pediatric and adult teams must be wiling to recognize thelr own limitations and be wililng to, learn from each other.**

10. **Internists must gain the patient's confidence in the old fashioned way; they must earn it.**

Any process that spawns a manual to guide the uninitiated through its phases is undoubtedly one that promises to be fraught with problems and impediments to success. The process of developing a model of health care delivery that assures the smooth transition of adolescent/young adult patients to appropriate adult health care settings is truly such a process. There are a variety of obstacles, on at least two levels, that must be considered. On the first level, attitudes and beliefs of health caregivers are the primary impediment to progress. Simply accepting the idea of transition and of the need to specially prepare the adult health care system to provide appropriate care acceptable to these patients and their families is difficult for some. These attitudes and beliefs must be understood, respected and dealt with before any success can be expected. Once these initial obstacles are overcome, the second level of the more practical impediments to transition must be addressed -who will do it? how will they learn to care for these patients? how will the process be financially supported? Sounds overwhelming!! Take heart -- with commitment, ingenuity and guidance from this manual, it can be done!

## Dealing with Feelings and Attitudes

A major impediment to starting the process of transition is the Pediatrician's feeling against transition and transfer of care. Several assumptions and beliefs may underlie that reluctance:

1. Pediatric caregivers can manage all patients regardless of age -- it is more important to be a specialist in the type of disease treated than in the treatment of a particular age group.

2. Adult patients can be comfortably and appropriately cared for in pediatric or adolescent wards with no detriment to their well-being. Patients like the familiar surroundings.

3. Pediatric nurses and house officers enjoy or do not mind caring for adult patients, particularly those they have known for years.

4. There is a historical paucity of caregivers in adult settings with adequate training in the specifics of care of the "pediatric disorders" -- they do not know how to care for these patients and have not bothered to learn. There is no reason for the pediatrician to take the initiative to get them interested.

5. It is painful to break long-established emotional bonds with patients and families and probably not worth it.

6. There will be negative economic consequences for the patients and the caregivers-- adult hospitals are "greedier" and the overall pediatric program may suffer if revenues from adult patients are lost.

Many pediatricians feel that to transfer patients after a certain age is to "dump" them. This view leads to feelings of guilt. In some situations, there are economic, professional and emotional disincentives for pediatricians to accept and actively seek transition for their patients. For many it may just be an inability or unwillingness to accept change. Most may wonder if the work and pain of initiating this process will be worth it. It, therefore, requires a high level of commitment from the pediatric caregivers to pursue the goal of developing appropriate health care in adult settings for the long-term survivors of pediatric disorders.

At the same time, feelings and beliefs of adult health care providers have also stalled the process of transition:

1. Adult caregivers are unfamiliar with "pediatric diseases" -- for established caregivers it may be uncomfortable to become "trainees" again. Being supervised on cases is for residents, not attendings.

2. These patients and their families are too demanding, too time-consuming and the patients are very immature.

3. Patients with chronic pediatric conditions are poorly insured and with DRG's will be an economic drain that is not desirable.

4. This type of patient may force the system to change its care patterns--what is done now is comfortable and works fine. Why should our system have to change to accommodate these patients who have been "spoiled" by the pediatric health care system.

5. The type of care these patients demand (team care, etc.) is not available in the adult care system and is costly to establish--administrators and caregivers will never accept the idea.

Many adult caregivers are unaware of the existence of the growing population of survivors of chronic pediatric conditions. If they are aware, they assume that such patients will not be particularly satisfying to care for or may be a drain on already strained resources. These caregivers, who are specialists in their own areas, may feel resentful or offended when pediatric professionals come to "show them the right way to care for patients". In addition, adult caregivers often feel that their pediatric counterparts assume that the teaching process is all one way--the pediatrician will show the internal medicine specialist the "right way" to provide care. Unfortunately,

this kind of approach negates the important contributions of adult specialists to develop better models of care for adult patients.

Despite the feelings and beliefs on both sides of the fence, the need for developing appropriate models of health care for survivors of chronic pediatric conditions is critical. Feelings can be acknowledged and overcome. Beliefs can change with information and experience. In the process of completing our project these issues had to be addressed and addressed again all along the way. The effort was, happily, worth it. Our beliefs about the positive benefits of transition for patients were confirmed. So......take the plunge!

## Charting Your Course

Thinking about obstacles can be discouraging, so for the remainder of the manual, we will turn the tables. Obstacles become challenges that lead to a series of goals and steps needed to meet those challenges. Achieve each of these goals and transition becomes a viable, workable process. Within each goal, there are specific steps or activities for pediatric caregivers, for adult caregivers and for the two groups together to attain.These goals and objectives were developed as a result of our specific experiences, but can be applied to the process no matter what the disease entity you may be treating or what configuration of health care settings are to be involved.

There are eight objectives that are basic to the development of a care model that will support a smooth, successful transfer of patients from pediatric to adult care:

- EXPLORE ONE'S COMMITMENT TO TRANSITION

- IDENTIFY INITIAL PARTNERS

- SECURE INSTITUTIONAL SUPPORT

- ASSURE ECONOMIC FEASIBILITY

- DEVELOP A STRUCTURE

- DEVELOP A SUCCESSFUL PARTNERSHIP

- ACHIEVE A SUCCESSFUL TRANSFER OF PATIENTS

Making the process work requires:

1. Assessing which goals you have achieved.

2. Planning the necessary actions to be taken to achieve those, as yet, unmet goals.

Charting your progress toward attaining each of the goals will help you plan your future actions. Each situation is unique and there will be different levels of progress toward each goal, depending on the current configuration of your health care setting, the history of relationships between pediatric and adult subspecialists and specific aspects of your locality, such as: reimbursement sources, geography and the demographics of the patient population.

Following your self-assessment, refer to the appropriate sections in the remainder of the manual for guidance on how to meet your goals and what step to take next. There are separate sections to guide the pediatric team and the adult health care team, as well as one which explores the tasks common to both teams.

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STOP
GO TO **SELF-ASSESSMENT** ON NEXT PAGES

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# SELF-ASSESSMENT

**Put a check next to each step you have already taken. Then decide on your next steps.**

GOAL 1.  Explore one's commitment to transition.

    **Pediatric Team Steps:**
\_\_\_\_\_    Examine willingness of all caregivers to give up care to others
\_\_\_\_\_    Examine willingness of all caregivers to put in extra effort to reach out to and train adult team.

    **Adult Team Steps:**
\_\_\_\_\_    Examine willingness to put in extra effort to gain support in adult system, to learn a new area and to modify methods of delivery of care.
\_\_\_\_\_    Examine willingness to be a "learner."
\_\_\_\_\_    Examine current commitments in relation to time needed to start a new project.

GOAL 2.  Identify initial partners.

    **Pediatric Team Steps:**
\_\_\_\_\_    Identify potential partners -- adult subspecialists.
\_\_\_\_\_    Make contact and secure initial agreement to plan together.

    **Adult Team Steps:**
\_\_\_\_\_    Identify interested M.D.s in key subspecialty.
\_\_\_\_\_    Determine level of departmental/partner interest in providing back-up to the interested M.D.

GOAL 3.  Secure institutional support for idea.

    **Pediatric Team Steps:**
\_\_\_\_\_    Gather general information about financial, service system, and academic impact of transition.
\_\_\_\_\_    Make presentation to administration and academic key players about impact/benefits of transition.
\_\_\_\_\_    Secure assurances that the program and the extra time needed to get it started have institutional support.

    **Adult    Team Steps:**
\_\_\_\_\_    Gather information about financial, service system and academic impact of taking on the new group of patients.
\_\_\_\_\_    Make presentation of material to administration and academic key players.
\_\_\_\_\_    Secure commitment to working on financial, staffing and moral support for this project.

**Self-Assessment Continued**

Joint Steps:

_____ Share information about demographics, costs, funding sources, academic benefits, etc.

GOAL 4. Assure Economic Feasibility.

Pediatric Team Steps:

_____ Gather specific information about patient payer mix.

_____ Assemble information about reimbursement sources' number of patients, long term needs for services, etc.

_____ Estimate financial impact of losing patients.

_____ Assemble information about length-of-stay.

Adult Team Steps:

_____ Obtain information about payer mix, reimbursement sources from Pediatric Team.

_____ Compare information about payer mix, etc. with own system costs.

_____ Consider effect of DRG's on costs/income.

_____ Obtain institutional commitment to financial support.

Joint Steps:

_____ Explore outside funding sources.

GOAL 5 . Develop a structure.

Pedlatric Team Steps:

_____ Develop mechanism for identifying "ready-for transition" patients.

Adult Team Steps:

_____ Develop team structure and meeting strategy.

_____ Develop structure of adult outpatient and inpatient care.

_____ Develop on-call and "coverage~ structure.

Joint Steps:

_____ Decide on an organizational structure and chart it.

_____ Establish a Transition Committee with members from each Team.

_____ Establish plan for observation of Pediatric Team by Adult Team.

_____ Develop plan for regular inter-team meetings.

_____ Develop a plan for the transfer of written records.

GOAL 6. Develop a Successful Partnership

Pediatric Team Steps:

_____ Examine attitudes and feelings of all pediatric caregivers.

_____ Secure commitment of pediatric caregivers to transition (including inpatient caregivers.)

_____ Develop awareness of what Adult Team can teach as well as learn.

_____ Develop a training program for Adult Team.

### Adult Team Steps:

_____ Examine attitudes and feelings of all adult caregivers.

_____ Secure commitment of Adult Team members to being "gracious" learners in pediatric setting.

_____ Participate in training program with Pediatric Team.

### Joint Steps:

_____ Set formal way to know each other's area of expertise.

_____ Set specific meetings to deal with inter-team concerns.

_____ Have key member on each team as inter-team "trouble-shooter."

_____ Utilize consultant or training materials for "team-building" activities.

GOAL 7. Achieve a successful transfer of patients.

### Pediatric Team Steps:

_____ Develop a timetable for preparing patients and families.

_____ Develop a program for preparing patients and families for transition.

_____ Secure acceptance of transfer by patients and families.

_____ Provide complete and timely information to Adult Team when patients are transferred.

### Adult Team Steps:

_____ Develop a timetable for meeting patients and families.

_____ Develop a system for meeting and assessing transition patients.

_____ Secure acceptance by patients and families.

_____ Provide feedback to pediatric caregivers about transferred patients.

_____ Train inpatient staff and consultation services on special aspects of care of transitioned patients.

### Joint Steps:

_____ Share information about successful and unsuccessful patient transfer to improve system.

_____ Develop plans for patients who cannot tolerate transfer.

There are seven major steps for preparing the Pediatric Team and guiding it through the actions it must take to make the transition process work.

1. Deciding to develop a partnership with an adult caregiver to provide a setting for adult patients.

2. Identifying a physician in the adult health care setting who has the skills and interest to become a partner.

3. Gaining support of pediatric academic and administrative authorities.

4. Examining attitudes toward transition with all pediatric caregivers and making a commitment to the process.

5. Developing a training plan for adult caregivers.

6. Developing a process for identifying and preparing patients appropriate for transition.

## Deciding to Develop a Partnership

Before deciding to contact a potential partner in the area of adult health care, the pediatrician must go through a process of self-examination and define his/her commitment to the concept of transition and willingness to effectively transfer care for his/her adult patients. Hesitation may be generated as a result of fear of losing too many patients, economic erosion of the program, opposition by others in the pediatrician's institution, etc. Other concerns include whether the pediatrician is ready to let go of patients and support them and the receiving team in the process--not to selectively transfer patients, i.e., THE ONES HE DISLIKES, keeping the ones he likes. The pediatrician will have to put in some effort to overcome the feelings of: "I have come this far with these patients and I do not want to give them away"; or "I do not want to give away the transitionable patients who are probably the ones who are most mature, doing better medically and less of a problemn. In addition, the pediatrician must face the issues of giving away information, a patient base for research, and income. Finally, the pediatrician must think about any possible resentment that might arise when having to teach other people in a relatively short time what may have taken a lifetime to learn. There can certainly be a feeling that "we are handing over these patients and all our knowledge and the adult team has done nothing to deserve it."

These negative feelings and concerns must be balanced by the realization that there are many benefits. Less time devoted to the patients lost may be more time to devote to other projects. Loss of the patient base for some types of research is balanced by

the ability to conduct collaborative research with experts in the adult care field. Finally, there may be a lessening of stress for the pediatric team as it shares the burden of caring for very sick and dying patients with another team of caregivers.

Of course the biggest incentive is providing one's patients with improved care that fosters their emotional and social growth. After having reviewed one's attitudes and feelings about the "issues of the heart" that relate to transition as well as the economic and practical issues, it is time to decide whether to forge ahead. These feelings will emerge over and over during the process of finding a partner and helping the adult program evolve.             Dealing with them before starting the process gives you a better chance of avoiding sabotage of progress by unresolved feelings.

Identifying a Partner

The easiest place to look is in one's own backyard. Usually partnerships of this nature are developed along institutional affiliation lines (i.e., university, hospital, group practice, HMO, etc.). If there is a program already in place, it makes more sense to utilize this structure and improve upon it. The adult practitioner you seek should be interested in the disease/disability you treat as an area of knowledge and interested to at least explore the possibility of doing chronic care in the manner that is necessary for the special needs of the population in question. Most adult subspecialists do have experience in chronic care, but may not see the need for a team or may not have the insight into the issues of chronic congenital or genetic disease. The partner must be sensitive, willing to learn, and not have a "big ego" that would prevent him/her from taking at least some direction from pediatric caregivers. This last point is critical, in our experience. It is very difficult for a practitioner who may have many years of experience to step back into the learners role again--going on teaching rounds as the student, being supervised in one's work, etc. It will be important for you to convey the need for training in a non-threatening way, so you can encourage potential partners.

Adult caregivers may be very busy and not appear immediately interested in the prospect of putting in the training and care delivery time that taking on a new patient population demands. Do not become discouraged if the internists or other adult caregivers do not jump at this golden opportunity. The process may sound more enticing if research possibilities are discussed. Sometimes a younger person, still looking for his/her "niche" may find this new area appealing. The economics of the situation need to be presented in a positive light. It may be useful to highlight the possibilities of outside funding for this new endeavor. There does, indeed, seem to be reason for optimism. In our experience, the adult team has received a great deal of special recognition within their institution as well as nationwide. The involvement with the new patient population has also led to inclusion in exciting new research arenas. In addition, the economics have not been problem for the adult care institution.

It is probably better to choose an individual who is not a section chief or has not been overwhelmed by administrative responsibilities. A lab researcher who does not have

care of these patients must become an important part of the partner's professional identity. He must see it as a means to professional advancement, a source of new learning and professional interest, or a source of professional satisfaction, not a nuisance or a drain of time and energy.

Having found a potential partner, the pediatrician will need to continue to reach out to the adult caregivers. The new partner will need support, training and guidance for some time. The pediatrician will have to coordinate the process, in collaboration with the partner, until a structure is developed and the adult team is trained and functioning independently.

<u>Gaining Support from Administrative and Academic Authorities</u>

The pediatric team will need the time and permission to begin the process of helping develop and train the adult team. To accomplish this, the project must have the support of the authorities in the system who must approve and support new efforts. In an academic setting this includes both academic and administrative authorities. Individuals such as section chiefs and departmental chairmen must see this as a desirable, academically correct step to take and in the best interests of the patients. Fears of debasing patient programs or losing crucial revenue must be addressed with concrete information. Information about the exact economic impact, the decreased need for resources and the ability to devote more time to other pursuits should be presented.

Administrative authorities must also be contacted. The same types of issues will arise. Administrators are particularly interested in the loss of revenue from decreased number of hospital admissions, decreased utilization of lab and other services, etc. Again, one needs to present the positive aspects of the shifts that can take place when these patients are transferred. Administrators may already be disposed to the concept since these patients may have poorer insurance or are outlayers in the DRG system. If you are located in a children's hospital, the administration may also be glad to rid themselves of the headache of caring for patients who are technically "too old" to be admitted under hospital by-laws. If there will be a substantial loss in revenues, it will be helpful to have ideas about developing other projects to replace the care of adult patients.

Before going to present the project, gather the information you may need to "make your case. It may be helpful to use the worksheet Identifying Patient Demographics for Planning the New Adult Health Care Program (page 13) to organize the fiscal information. (Save this information, because your partner will need the exact same information to gain support in his/her care setting.) In addition make a list of potential academic advantages (new types of research possible with skills of adult caregivers; studying the process of transition; new training opportunities for students and house staff, etc.) and new revenue sources. You can use the worksheet, Contact Check List for the Pediatrician, to make sure you have covered all the bases (page 14).

## Identifying Patient Demographics for Planning
## the New Adult Health Care Program

This data should be obtained from the pediatric unit for planning the new adult program. This format can also be used to continue to maintain information about the progress of the new adult unit once it is established.

**IN-PATIENT**
Total Patients Registered (over 18) _____

Total Patients Admitted (from _____to _____) _____

Total Number of Admissions (from _____to _____) _____

Average Length of Stay _____

Median Length of Stay _____

Average Number of Patients In-House _____

Services Utilized
_____
_____
_____
_____
_____
_____
_____

**OUT-PATIENTS**
Number of Visits (from _____to _____) _____

Number of Patients (from _____to _____) _____

Number of New Patients (from _____to _____) _____

Services Utilized
_____
_____
_____
_____
_____
_____
_____

## Contact Checklist For the Pediatrician

The following is a convenient checklist to assure contact with individuals important in the process of establishing a new program.

\_\_\_\_\_ Section Chief

\_\_\_\_\_ Department Chairman

\_\_\_\_\_ Hospital Administrator

\_\_\_\_\_ Individual Disciplinary Departments

    \_\_\_\_\_ Nursing

    \_\_\_\_\_ Social Work

    \_\_\_\_\_ Dietary

    \_\_\_\_\_ Physical Therapy

    \_\_\_\_\_ Respiratory Care

    \_\_\_\_\_ Psychology

    \_\_\_\_\_ Other

\_\_\_\_\_ Fiscal or billing office for Financial Information

Examining Attitudes Toward Transition with the Pediatric Team

Once you have worked your way through the first steps and are onto the next ones, it is important to begin discussing the possibility of a transition program with your own care team. Be sure to show enthusiasm and commitment. Remember all the feelings and attitudes you struggled with before coming to the conclusion to move ahead with transition. Your team members will have to go through the same process Be supportive, but also do not allow the process to be diverted by their concerns. They will need to discuss how to deal with shortcomings of the other team, how to have patience and give of oneself in the pursuit of the ultimate goal. This will mean accepting mistakes, trying to control derisive remarks, and not expressing negative feelings in front of patients. If a particular team member has extremely strong negative feelings, these must be addressed in a private meeting. The team should set aside times to meet alone and with the adult team as it develops to discuss concerns and feelings, so they do not fester and undermine the process.

The concept must also be introduced to professionals outside the team, but within the same care setting. Nurses on the pediatric in-patient unit to which our Cystic Fibrosis patients had been admitted felt that they needed to understand and feel comfortable with the transition process and the new care setting so they could help inpatients begin to accept the new setting. Visits to the new care setting, a complete understanding of how a patient's care will be transferred, and personal meetings with the new caregivers are part of that process. All personnel must understand your concept of transition. Feedback about why particular patients are or are not transitioned helps the other staff members understand the concept. In our experience, one concept that needed repeating was that transition did not occur automatically at a "magic age". This idea was frequently mentioned by floor nurses, often in hopes that a particularly difficult patient would be sent on to ths adult setting. Inpatient staff also need help in understanding "failures" of transition-sometimes the feelings of a patient who has elected to return to the pediatric setting can quickly color staff opinions of the adult program if the pediatric team does not provide accurate feedback. Please be sure to let all caregivers in the pediatric setting know about the successes! It helps them to be positive, enthusiastic advocates for transition with younger patients and their families.

You can use the Consolidation of Commitment Checklist (page 16) to help you touch all the bases in this process.

## Consolidation of Commitment Checklist

_____ Present idea to team.

_____ Facilitate team discussion of feelings.

_____ Facilitate ongoing inter-team meetings to deal with feelings and
concerns.

_____ Present idea to non-team staff.

_____ Allow inpatient staff to know and visit new program.

_____ Explain rationale of transition and selection process to non-team
staff.

_____ Insure feedback about transferred patients for non-team staff.

_____ Educate non-team staff about reasons for failures to prevent
"rumors".

Developing Training Program

Training the adult caregivers is an ongoing process. Much of this training will come within the context of shared care and rounds. It is important to have a total structured program, however, in order to assure the quality of adult care. A training program should be planned considering the following components:

1. A bibliography compiled by each team member for the members of the Adult Team.

2. Meetings between same discipline members of each team.

3. Teaching rounds in both the outpatient and inpatient pediatric care setting for all Adult Team members. (This experience is to expose them to both the details of care and the relationships among team members.)

4. Supervision of cases relating to disease specific information. Styles of caregiving should be addressed carefully. Remember the reason you are doing this is to expose patients to a different mode of care delivery. Some hints are O.K., but be careful!

5. System of telephone consultations with pediatric team.

6. Inpatient pediatric nurses should help the adult team nursing coordinator plan and execute training of adult inpatient nurses.

7. Concensus of care conferences.

8. Compile specific treatment protocols to assist in condition of care.

Developing a Process of Identifying and Preparing Patients

Preparing patients and families for the move to the adult health care setting is part of a total process of helping the patients grow up. We found that having a separation point helped focus our efforts toward assuring patients' understanding and independence needed in adulthood. The process starts many years before the patient and family ever meet the adult care team. The following timetable was developed for our setting:

• Patients are helped to take responsibility for medications and treatment at as early an age as possible (by ten at latest.) The adult team is mentioned as a long-term, future goal to pre-adolescents--for when they are "ready".

• At age thirteen, patients are seen by themselves during routine outpatient visits. Parents are invited to join the session later. The patients are expected to be able to respond to questions about their symptoms, treatments, etc. Parental involvement is encouraged to become more supervisory and less active.

- A planned re-education program for each adolescent is carried out. Understanding of disease, rationale of therapies, source of symptoms, recognizing signs of worsening and what to do about it, how to seek help from health professionals, how to best work the medical system and, for older adolescents, insurance issues are included.        At age fifteen-and-a-half to sixteen, a detailed explanation of the Adult Program is given to the patient and family, suggesting that most people are ready to start seeing the adult team at age 16.

- Between the ages of 16-18, after discussion of readiness by the Pediatric Team, the adolescent has a first official visit with the adult team in the pediatric clinic. Following that visit, patients and families are encouraged to voice their feelings both positive and negative to adult team members and the pediatric nurse. At this time similarities between teams are emphasized and concerns addressed.

- Subsequent office visits are held with the pediatric and adult teams until the patient is deemed "ready." The patient and family are invited to tour the adult facility and to address questions and concerns to the adult team. A brochure is provided about the adult program's facilities. It includes a map with directions from key access routes along with contact team members' phone numbers. A fact sheet of key departments at the adult facility is also provided.

The decision that a patient is "ready" for transition must be made by the entire team, with input from the patient and family. This assessment can occur in a number of ways, but should be organized and standardized for your team. In this project, the pediatric Clinical Nurse Specialist gathered information from the patient, family and team and then addressed the following set of issues:

1. Does the patient take responsibility for his/her own care most of the time?

2. Does the history the patient gives of his/her disease/life correlate with the team's knowledge of the history?

3. Do the parents no longer persist in saying "I can't make him/her take his/her medications?

4. Has the patient been In the pediatric Inpatient unit less than 2-3 times In the past year?

5. Can the patient describe the symptoms of an exacerbation in illness?

6. Does the patient ask to speak directly with the health care team?

8. Is the patient developing clear vocational and future oriented goals?

9. Can the patient make the change without experiencing a particularly acute loss of the relationship with a particular pediatric team member?

If the answer to all the questions is "yes", then the patient is deemed ready for transition. If the answer to any question is no, then a plan is made for services such as counseling with the pediatric team social worker, education about medical issues with the pediatric team nurse or other personnel, special support from a team member to whom the patient has been very attached to move on, etc. (If the patient has been frequently hospitalized in the past year, transition proceeds only if the patient and family express a desire to move to the adult setting.) A checklist, **What Patients Need to Know About Their Disease** (page 20), was developed to help both teams assess knowledge. The patient is then reassessed to determine readiness. This assessment process provides only a guideline to the team. Some patients may be able to transition to the adult team, with the recommendation for further services in problem areas from the adult caregivers.

## What Patients Need to Know About Their Disease Checklist

_____ What is Cystic Fibrosis?

_____ Genetics of Cystic Fibrosis (handout).

_____ Treatment regimen:
    _____1.  Antibiotics
    _____2.  Aerosol
    _____3.  Chest PT
    _____4.  Inhalers
    _____5.  Nutrition
        _____a.  Enzymes
        _____b.  Vitamins
    _____6.  Exercise

_____ Complications (if applicable):
    _____1.  Hemoptysis
    _____2.  Pneumothorax
    _____3.  Diabetes mellitus
    _____4.  Arthritis

_____ Help in coping:
    _____1.  Employment
    _____2.  Peers/communication
    _____3.  Lifestyle/image changes
    _____4.  Insurance
    _____5.  Family planning
        _____a.  Birth control
        _____b.  Adoption
        _____c.  Artificial insemination
    _____6.  Life expectancy

_____ Other:
    _____1.  Usage of $O_2$
    _____2.  Heart/Lung transplant

# Steps for the Adult Team

There are five major steps in formulating and preparing the adult team:

1. Identifying a physician to direct the medical unit.

2. Identifying the other disciplines to participate on the adult team.

3. Recruiting and financially supporting the team members.

4. Developing a cohesive team.

5. Educating and training the team.

6. Preparing other caregivers.

## Identifying a Physician

To initiate an adult unit, typically, direction for adult care needs must come from the pediatric unit. The identification of a physician in the adult setting implies finding an individual who has a personal interest in the population and sees developing this unit as consistent with his/her own career development. Once such an individual is identified, he/she must take leadership within his/her own institution and begin discussions with the section chief and departmental chairman. Enlisting the support of the department head and section chief is critical for the success of the program. Discussions may center around the need for the medical care, the financial viability of the program, and the academic potential such as training and research.

## Identifying Other Disciplines

In planning an adult program for young adults with chronic illnesses, team care is essential. The disciplines involved in the team will depend upon the nature of the disease and accompanying disabilities. In developing the adult, it is helpful to first examine the components of the pediatric team from which patients will be transitioned. Usually the disciplines involved in the pediatric team will be similar to those needed for the adult unit. There clearly will be some variability. For example, on some pediatric teams special education will be a significant component, while for teams dealing with young adults, vocational rehabilitation may be a more appropriate and related service.

Using cystic fibrosis as an example, the following disciplines were essential for establishing the team:

1. Nursing to coordinate patient care, team activities, and communication with the pediatric team. (A master's level clinical nurse specialist is recommended, due to the multiple demands of the role on this sort of team.)

2. Social Work to support the patient and family around financial issues, life planning and coping with the patient's disease.

3. Nutrition to plan an adequate dietary program for each patient and provide patient education around nutritional issues.

4. Physical therapy to provide chest physiotherapy and physical training programs for patients.

<u>Recruiting and Financing the Team</u>

Before recruiting any team members, it is essential to enlist the support of the hospital administration. Hospital administrators will be interested in all aspects of financing of the program such as the payer mix, DRG reimbursement, average length of stay, resource allocation for the specific disease, whether or not a supplementary state program exists, and the number of personnel requested. Information on potential special support from public agencies, private foundations, drug companies, and individual donors will be important to ascertain. (See **Cystic Fibrosis Program Financial Projection Summary and Payer Mix for Total Number of Patients Registered, and Identifying Patient Demographics for Planning the New Health Care Program,** pages 23, 24, 25.)

# CYSTIC FIBROSIS PROGRAM FINANCIAL PROJECTION SUMMARY

|  | ACTUAL FY86 | PROJECTED FY 87 |
|---|---|---|
| TOTAL NUMBER OF ADMISSIONS | _____ | _____ |
| GROSS CHARGES (Billed Services) | _____ | _____ |
| NET REVENUE (Collections after write-offs, etc.) | _____ | _____ |
| COSTS (Determine through hospital administration) | _____ | _____ |
| GAIN/LOSS | _____ | _____ |

NOTES_____

_____

## Payer Mix for Total Number of Patients Registered

| Primary Payer | Number of Patients | % of Total # of Patients |
|---|---|---|
| Blue Cross | _____ | _____ |
| Medical Assistance | _____ | _____ |
| Medicare | _____ | _____ |
| Commercial | _____ | _____ |
| CF-State | _____ | _____ |
| Self-Pay | _____ | _____ |
| TOTAL | _____ | _____ |

<u>Charges and Costs</u>

Total Charges In-patient (from _____to_____) _____

Total Costs In-patient (from _____to_____) _____

Net Revenue _____

Total Charge Out-patient (from _____to_____) _____

Total Costs Out-patient (from _____to_____) _____

Net Revenue _____

# Identifying Patient Demographics for Planning
# the New Adult Health Care Program

This data should be obtained from the pediatric unit for planning the new adult program. This format can also be used to continue to maintain information about the progress of the new adult unit once it is established.

**IN-PATIENTS**

Total Patients Registered (over 18) _____

Total Patients Admitted (from _____to_____) _____

Total Number of Admissions (from_____to_____) _____

Average Length of Stay _____

Median Length of Stay _____

Average Number of Patients In-House _____

Services Utilized _____
_____
_____
_____

**OUT-PATIENTS**

Number of Visits (from_____to_____) _____

Number of Patients (from_____to_____) _____

Number of New Patients (from_____to_____) _____

Services Utilized _____
_____
_____
_____

Having gained the support of the hospital administration, the next step will be to contact each department that will be involved in the program such as nursing, social work, dietary, etc. Initial contacts should include discussions about the importance of the program, the structure of the program, and the potential role for the discipline. A strategy for discussing the role of the department in the program will be to articulate the support of the administration for the program and commitment to hiring personnel for adequately staffing the program so that the new program will not create an extra burden for the department. In planning for staffing, both in-patient and out-patient responsibilities must be considered. (See Contact Checklist for Initiating a New Adult Health Care Program,        below.)

### Contact Checklist for Initiating a New Adult Health Care Program

The following is a convenient checklist to assure contact with individuals important in the process of establishing a new program.

\_\_\_\_\_   Section Chief

\_\_\_\_\_   Department Chairman

\_\_\_\_\_   Hospital Administrator

\_\_\_\_\_   Individual Disciplinary Departments

   \_\_\_\_\_   Nursing
   \_\_\_\_\_   Social Work
   \_\_\_\_\_   Dietary
   \_\_\_\_\_   Physical Therapy
   \_\_\_\_\_   Respiratory Care
   \_\_\_\_\_   Psychology
   \_\_\_\_\_   Other

\_\_\_\_\_   Medical and Surgical Departments (to provide consultations)

   \_\_\_\_\_   ENT
   \_\_\_\_\_   Gynecology
   \_\_\_\_\_   Urology
   \_\_\_\_\_   Gastroenterology
   \_\_\_\_\_   Diabetology
   \_\_\_\_\_   Rheumatology
   \_\_\_\_\_   Other

The department heads will share a leadership role in the recruitment of staff with the Medical Director of the program. In some disciplines this will be a difficult process because of the lack of trained personnel. A number of "pediatric diseases" in question are not known to health professional caring for adults; thus, it is difficult to find trained professionals. For example, in the cystic fibrosis program, it was possible to identify a nurse who had good experience in coordination of patient care and program administration but not with cystic fibrosis patients. Job descriptions for each position should be developed. Using the pediatric team's job descriptions may be a good starting place.

There was some initial discussion in planning our program about having the pediatric Clinical Nurse Specialist transfer to the adult care setting to be the Adult Team coordinator. There were several obvious advantages to this course, since she would then be familiar with the disease and the issues that the patients and families faced. In addition, she could play a major role in training the adult team members, as well as the inpatient nursing staff at the adult hospital. We quickly rejected the idea, because it undercut one of the important reasons for transition--a change to an adult oriented manner of providing care. The point of transition was to have caregivers with attitudes that were different than their counterparts in the pediatric setting. Having a pediatric caregiver coordinate the adult team, would have been counter-productive. Thus, we chose to take the time and effort to train an adult oriented nurse about the disease issues. The same principal applied across disciplines.

Developing a Cohesive Team

Once team members have been recruited, forming the adult team is a major task. Establishing the roles and responsibilities of each team member, gaining an understanding of each other's roles, assuring good communication within the team, and providing leadership for the team are the key objectives.

For establishing roles and responsibilities clear job descriptions must be developed to include both in-patient and out-patient responsibilities. As the program develops emphasis in roles may change and staff should be prepared for these changes. **Adult Care Team Job Descriptions** (page 28) is a summary of several job descriptions from the cystic fibrosis program that illustrates the service, administrative, and linkage functions of each of the professionals.

Adult Care Team Job Descriptions

<u>Physician</u>

**Disciplinary Duties:** Provide medical services to Cystic Fibrosis adult patients on a inpatient and outpatient basis; teach medical students, housestaff, fellows and colleagues about Cystic Fibrosis care.

**Team Linkage Functions:** Serve as medical director and coordinator of the overall adult program; fiscal administrator of program; liaison with the Medical Director at the Pediatric Center; representative and advocate of the program within the hospital and departmental administrative systems.

<u>Nurse Coordinator</u>

**Disciplinary Duties:** Provide direct care (teaching, counseling, assessments and medical treatments); take patient calls and act as a resource for patients about needed medical services (e.g. home care, equipment); provide education and consultation to in-patient nursing staff about Cystic Fibrosis care and related issues; develop patient education programs.

**Team Linkage Functions:** develop policies and procedures in relation to Cystic Fibrosis Program; coordinate care provided by multi-disciplinary team to inpatients and outpatients; facilitate communication among team members about team function and patient care; facilitate communication between Cystic Fibrosis team and inpatient nursing staff.

<u>Social Worker</u>

**Disciplinary Functions:** Do complete psychosocial assessment of all patients considered for Transition program and identify problem areas needing intervention; provide counseling and other interventions to aid in adjustment to transition and enhance growth and independence; develop support groups .

**Team Linkage Functions:** Communicate and discuss plan with team both verbally and in the written record; assist the team in determining patient's appropriateness for transition and possible issues of concern; work with other team members in development of a total care plan for patient and family.

<u>Dietician</u>

**Disciplinary Functions:** Visit inpatients within 24-48 hours of admission to do initial nutritional assessment and make recommendation for nutritional needs, set up appropriate meal pattern; arrange for supplemental feedings when necessary; and make recommendations for nutritions support regimens (TPN, etc.) and make recommendations re: use of pancreatic enzymes An outpatient clinic will provide consultation to patients, and develop or acquire information for patients related to nutrition.

**Team Linkage Functions**: Provide consultation to team members on nutritional issues; communicate diet plan in writing and verbally to team; conduct research with team; attend patient conferences to aid in total care plan development.

<u>Physical Therapist</u>

**Disciplinary Functions**: Deal with equipment needs inpatient; provide chest Physical Therapy (pulmonary hygiene and toilet); develop rehabilitation plan including assessing motion, strength, posture and ambulation and prescribing appropriate exercises to increase aerobic endurance and lead to a safe resumption of pre-admission life.

**Team Linkage Functions**: Develop overall care plan with team; provide consultation to team members about Physical Therapy and equipment issues; report verbally and chart Physical Therapy activities.

Understanding each person's role is essential for the smooth functioning of a team. Sharing job descriptions is a first step in this process. Devoting team meeting time to sharing perceptions of each others roles is a way of establishing a good communication process and of developing rapport among team members. As the team progresses in its work together, a simple exercise the teams can use to assure ongoing communication about roles and responsibilities is the **Role Message Exercise**. (see **Role Messages Exercise and Role Messages Format**, pages 30 and 31.)

# Role Messages Exercise

A simple process for examining and intervening in role definition problems has been developed for use with health teams. The process has four basic steps:

Step 1      Share mutual role expectations by writing "role messages".

Step 2      Identify role ambiguities and conflicts generated in the role messages.

Step 3      Discuss alternatives and negotiating the best, most realistic, solution.

Step 4      Implement a "role agreement" that specifies role expectations and commitments.

A role message is a written note to a fellow group member (one should be written by each team member to every other team member). Using the form on the next page each team member can then draw-up a tally for him/herself in each category (more of, less of, same as) making a sheet with a column for each category. This helps each member to identify problem areas. The input and response form the basis of negotiating sessions with the entire team to develop agreements about role functions. Obviously, institutional rules and regulations may have to be considered here as well. For more details on this process read: Module Four and Five in Improving the Coordination of Care: A Program for Health Team Development by 1. Rubin, M. Plovinick and R. Fry. This approach is adapted from: Rubin, Irwin, M., Plovnick, Mark S., & Fry, Ronald E. Improving coordination of care: A Program for health team development. Cambridge, MA: Ballinger Publishing Co., 1975.

Role Messages Format

TO:

FROM:

(fill in whatever is appropriate to any group task)

In order to help me
_____
_____
_____

I need you to do:

1.  More of:
_____
_____
_____
_____

2.  Same as
_____
_____
_____
_____

3.  Less of:
_____
_____
_____
_____

This approach is adapted from: Rubin, Irwin, M., Plovnick, Mark S., & Fry, Ronald E. Improving coordination of care: A Program for health team development. Cambridge, MA: Ballinger Publishing Co., 1975.

To assure communication among team members takes time and commitment. Regular team meetings are essential to discuss patient issues as well as communication issues among members. The cystic fibrosis team conducts a team meeting after every out-patient clinic day, periodically during the stay of any in-patient, and others times as needed. All team members have access to written records and have a designated place in the chart for writing notes. When new teams are formed, it is sometimes useful to conduct a series of team building sessions. An outside facilitator skilled in team building can be helpful in conducting these sessions. A variety of techniques can be used to accomplish this. See Team Building Program Activities   (below) for a few suggestions.

## Team Building Program Activities

- Pick a regular team meeting time. At first you may use this time to get to know one another and plan how your team will function. Later this meeting will be used to plan patient care and develop programs.

- Develop a structure for case management. Who will see that all appropriate services are provided? Who will communicate needed information to all team members? Who will act as a liaison between the team and outside agencies or consultants? Typically, the nurse will act as the coordinator, but this may vary from setting to setting.

- Clarify roles of the various team members. (See Role Messages Exercise,     page 30). There are many overlapping areas of expertise and responsibility on a team. For the team to function smoothly, each team must decide how decision making and work will be divided.

- Develop a system of team communication. Is there one person who will always be sure others hear of events, information about patients, etc.? Are there mailboxes for all team members in a central place? Do they all carry pagers?

- Consider having the team housed as close  together  as  possible  or  have  some space that team members can share when doing team activities. Patient records may be kept here as well. Frequent contact is an important component  of  the team developing an identity.

- Consider having members' name tags and business cards identify them as members of the team.

- Social events can solidify a sense of team identity.

- "Retreats"--taking time away from  the  workplace  to  concentrate  on  improving team functioning.

Team leadership has several aspects that should be addressed. Clearly the physician is the director of the medical program, but in terms of total patient care all team members are equal partners. Depending upon the presenting problem at a given point in time, leadership around the solution may vary. Every team needs a constant facilitator who takes responsibility for calling the meeting, conducting the meeting and seeing that all members actively participate. This facilitator may or may not be the medical director. Sometimes these responsibilities are shared among more than one team member. Frequently the nurse, because of her coordination responsibilities for patient care, will take this role. See Leadership Assessment (page 34) for suggestions.

# Leadership Assessment

There are at least two types of leadership needed for any group to work effectively;

Task Leadership    --    making sure that the goals of the group
                        are met.

Process Leadership --    making sure that interpersonal interactions
                        among team members run smoothly.

It is rare for one person to be equally effective in both areas of leadership. Usually these leadership roles may be shared among several team members. Occasionally a team is made up in such a way that there is no one who can exercise one of these needed forms of leadership. Other times, a team leader cannot see the importance of both types of leadership and team functioning suffers. As your team evolves it may be helpful to assess the leadership needs for the group at that time. Asking team members to fill out the following checklist (anonymously) may help the team coordinator assess the effectiveness of leadership on the team:

|  | YES | NO |
|---|---|---|
| Most members are committed to the mission of our team. | | |
| Our team has fommulated clear goals. | | |
| The atmosphere on our team makes it easy for me to make a useful contribution. | | |
| Our team encourages all members to participate. | | |
| I feel our team is productive in meeting its goals. | | |
| Our team meetings are run effectively. | | |
| I am clear about my responsibilities to the team. | | |
| I trust the other members of our group as we work toward our goals. | | |
| Most members feel good about being part of this team effort. | | |
| There is recognition for a job well done on this team. | | |

It is also helpful to get some idea about which team memebers have recognized leadership ability in one or both leadership areas.  You will clarify your roles as caregivers an dteam members using the **Role Messages Exercise**     (page 30) Now you can clarify leadership roles on the team using the following exercise.

### Personal Profile of the Kinds of
### Contributions I Make to My Team

| Types of Contributions Related to Our Task | I see myself as good at | Others see me as good at |
|---|---|---|
| Initiating | | |
| Giving Suggestions | | |
| Giving Opinions | | |
| Giving Information | | |
| Seeking Suggestions | | |
| Seeking Opinions | | |
| Seeking Information | | |
| Elaborating and Clarifying | | |
| Summarizing | | |

| Types of Contributions Related to Our Team's Process | I see myself as good at | Others see me as good at |
|---|---|---|
| Encouraging | | |
| Harmonizing | | |
| Compromising | | |
| Relieiving Tensions | | |
| Supporting Other Member | | |

## My Profile of Contributions
## Other Team Members Make

| Types of Contributions Related to Our Task | Individuals Who are Good at This On Our Team |
|---|---|
| Initiating | |
| Giving Suggestions | |
| Giving Opinions | |
| Giving Information | |
| Seeking Suggestions | |
| Seeking Opinions | |
| Seeking Information | |
| Elaborating and Clarifying | |
| Summarizing | |

Each member should fill in this checklist anonymously.  See directions on next page for tallying results.

| Types of Contributions Related to Our Task | Individuals Who are Good at This On Our Team |
|---|---|
| Initiating | |
| | |
| | |
| Giving Suggestions | |
| | |
| | |
| Giving Opinions | |
| | |
| | |
| Giving Information | |
| | |
| | |
| Seeking Suggestions | |
| | |
| | |
| Seeking Opinions | |
| | |
| | |

After team members fill in this checklist anonymously, someone tallies the group profile and presents a consolidated picture of how members perceive each other. Each member can see whether he/she sees him/herself the way others on the team do. More importantly for the group, the team can see if leadership styles are lopsided (too much task and no atmosphere) or whether there is some critical component of needed changes themselves. Other times, outside consultation is needed to unravel the team's difficulties. The following are RED FLAGS that indicate a team may need help from an outside consultant:

Is the current leadership on the team overwhelming to most group members?

Is there an unwillingness to assume leadership on the team?

Is the group unable to confront the leader or resolve the issue of absence of leadership?

Is there widespread apathy on the team, rendering it ineffective?

Is there conflict within the team that continuously prevents the team from resolving issues or focusing on the task?

Are team members rapidly losing interest in the work of the group?

Is the team continuously unable to reach effective decisions?

Does the team spend a lot of time on problems/issues without taking any action steps?

---

### Sample Tally of Leadership Contributions for Team

| Type of Contribution | Tally Profile |
|---|---|
| Initiating | Tom (4), Barbara (2), Jim (8) |
| Giving Suggestions | Carolyn (6), Tom (2), Alice (1 ) |

---

This approach to leadership assessment is from: Magrab, Phyllis, *Human factors in interagency teams.* In Magrab, P., Elder, J., Kazuk, E., Pelosi, J. and Wiegerink, R. Developing a Community Team, prepared for HEW interagency Task Force under Grant # 54-P-7147613-02 by American Association of University Affiliated Programs.

## Educating and Training the Team

The adult team needs to develop a knowledge base around a disease about which it may not be familiar and evolve a philosophy of care that is consistent with the needs of the patients and the families. Adult health care professionals more typically are not team oriented and are not accustomed to responding to patients who have conditions emanating from childhood. This has important implications for designing training and education experiences. Issues related to sex, marriage, pregnancy, child rearing, jobs, morbidity, code status and prognosis are other important areas to consider in evolving a philosophy of care. These are issues adult health care specialists deal with more comfortably.

Using the cystic fibrosis program as an example, the following kinds of training an educational activities are important:

1. Dissemination of relevant literature.
2. Informal reporting to one another on issues important to each other's. discipline -- such as the social worker talking about the financial problems related to the patient population, etc.
3. Inservices by team members on topical issues of importance to all the team members.
4. Lectures from the pediatric team on the disease process itself, aspects of care such as nutrition, etc.
5. Formal rounding with the pediatric team.
6. Attendance at pediatric team meetings.

## Preparing Other Caregivers

In developing an adult program, there are health professionals outside the immediate team who will be important in the process. These include other physicians who provide back-up coverage for the patients, the head nurse and floor nurses on the inpatient unit, and house staff and fellows in the section.

For the physicians who provide additional coverage for the patients, it is critical to instill a philosophy of care as well as a sufficient knowledge base so that they are compatible with the program. To accomplish this, a variety of informal experiences coupled with a few formal educational activities are necessary. These physicians should be encouraged to attend a few out-patient clinics and subsequent team meetings on a regular basis so they have a familiarity with the program and the patients. They should attend several in-patient rounds. A few well structured lectures on the nature of the disease, disease management and team care should be offered. Through their informal relationship with the medical director of the program they will have an opportunity to observe an effective role model.

The head nurse is a vital link in the continuity of care of these patients. Integrating these patients onto the in-patient unit will take preparation of the floor nursing staff. Using the cystic fibrosis program as as example, a good working relationship between

the team and the in-patient unit was accomplished by the nurse coordinator of the team and the head nurse of the in-patient unit meeting to discuss the needs of young adults with cystic fibrosis. Through these meetings key issues were identified: **promoting independence of the patient, providing emotional care, scheduling meal times and aerosol-chest physiotherapy, and establishing changes in the I.V. policy to maintain the same line.** These issues were then addressed through inservices and the development of the **Cystic Fibrosis Patient Guidelines** (page 41). This sheet is useful not only for the nurses but for the interns and the residents as well.

The interns, residents and fellows will all require preparation for providing care to these patients. The interns and residents should receive inservices and go on rounds with the medical director. The fellows, while they are on rotation, participate in all clinics, team meetings, conferences, and in-patient rounds. A few special lectures are designed to teach the fellows about the disease as well as the philosophy of care for these patients and their families.

<p style="text-align: center;">Cystic Fibrosis Patient Guidelines</p>

## I. TESTING

### Admission Labs
1. CBC with differential
2. Chemistry Admission Package
3. UIA
4. ABG or 02 SAT
5. Sputum C&S -- state patient has CF (needed for Cepacia)
6. Chest x-ray
7. Theophylline level if on a theophylline drug
8. Spirometry

### During Treatment
1. CBC with differential
2. Tobra Levels -- peak and trough
3. Theophylline levels, prn
4. Pulmonary function tests after 2 weeks of treatment -- predischarge
5. UA, BUN and Creatinine, weekly
6. Bedside portable 02 if needed
7. Abdonimal ultrasound prn
8. Vitamin E level

### Before Discharge
1. CBC
2. Chemistry package
3. Chest x-ray if needed
4. Sputum on discharge
5. Complete pulmonary function tests or spirogram on discharge

## II. PATIENT MANAGEMENT:

Continue patient's normal pancreatic enzyme (Pancrease or Cotazyme S) 1-3

tablets with meals; 1-2 with snacks. Pancreatic enzymes are to be kept at bedside.

Vitamin Therapy to be continued.

Hep Lock only to be changed with signs of early infiltration.

Aerosol therapy with_____and 2 cc N.S. tid or Qid basis followed by Chest Physical Therapy (Nursing will assign specific times).

Please avoid any unnecessary "sticks" Order a.m. labs to be drawn with levels.

No invasive-treatments or diagnostic studies after 8:00 p.m.

The aminoglycosides: Tobramycin, Gentomicin, Amikacin -- will be on a Q6 (10-410-4) schedule to ensure proper peak and trough levels and inactivation of amino glycoside with other antibiotics. All other penicillins should be on an alternate schedule.

After 12:00 am an IV solution will run KVO with piggyback antibiotic for ease of administration and patient consideration for sleep.

Calorie counts will be done on all patients for the first 3 days of hospitalization and prn therafter.

Weights daily.

Double House Diet with extra salt. Nutritional supplements as recommended by the nutritionist.

Humidifier  -- prn.

III. CF TEAM TO BE CONSULTED ON PATIENT'S ADMISSION

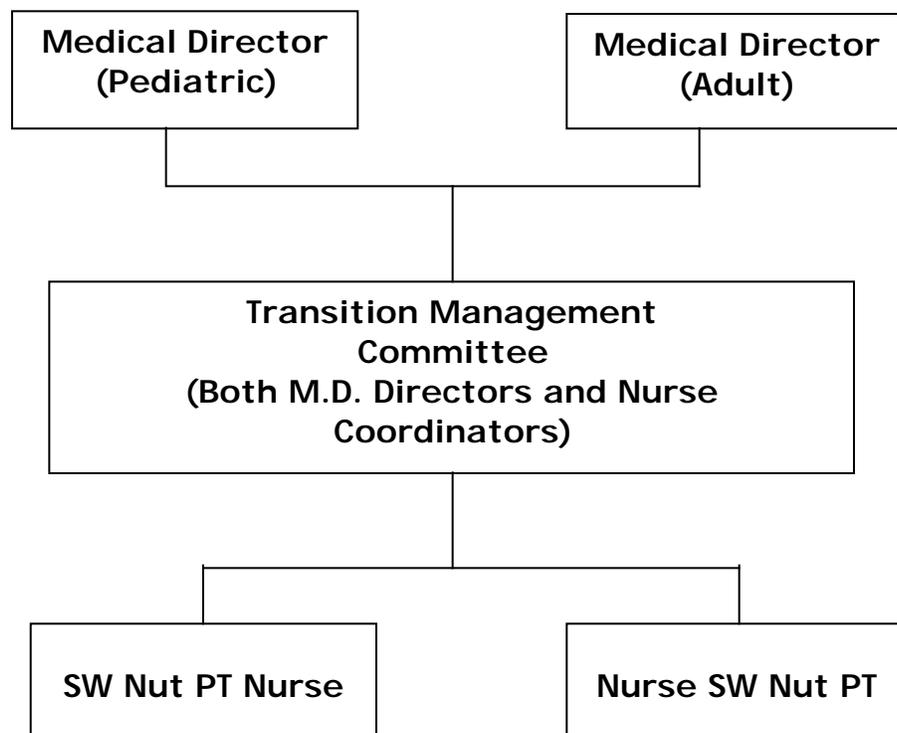|  | Name(s) | Phone/Beeper # |
|---|---|---|
| Physician |  |  |
| Nursing |  |  |
| Social Services |  |  |
| Nutrition |  |  |
| Physical Therapy |  |  |

There are two main steps for the teams to address jointly:

1. Developing a structure for the transfer of care

2. Building inter-team relations.

### Developing a Structure for the Transfer of Care

Organizational Structure

The overall organizational structure of the transition effort will vary depending upon a variety of parameters related to the specifics of the program (e.g., number of institutions involved, the organizational structure of each institution, etc.), but the structure of the actual transition effort should be similar regardless of these differences. The following organizational chart represents a recommended model for structuring the transition program.

```
┌──────────────────┐         ┌──────────────────┐
│ Medical Director │         │ Medical Director │
│   (Pediatric)    │         │     (Adult)      │
└──────────────────┘         └──────────────────┘
          │                           │
          └─────────────┬─────────────┘
                        │
         ┌──────────────────────────────┐
         │    Transition Management      │
         │         Committee             │
         │ (Both M.D. Directors and Nurse│
         │        Coordinators)          │
         └──────────────────────────────┘
                        │
          ┌─────────────┴─────────────┐
          │                           │
┌──────────────────┐         ┌──────────────────┐
│  SW Nut PT Nurse │         │  Nurse SW Nut PT │
└──────────────────┘         └──────────────────┘
```

For managing the transition program a Transition Management Committee should be established across the two institutions. The organizational chart reflects the minimum

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membership of this committee-the two physician directors and the two nurse coordinators. This committee serves a policy making and trouble shooting function for the program.

## Administrative and Patient Care Meetings

From the outset joint team meetings are at the heart of an effective transition program. Time spent in developing good communication between the teams early on is a key to smooth and efficient transfer of patients as the program becomes established.

Initially, the adult team can begin by observing the pediatric team to become familiar with the patients and the style of care. These meetings typically can occur weekly following the pediatric clinic. In addition at this time the adult team members may attend several pediatric clinic sessions as discussed in the previous section. It should be noted that sometimes the adult physician will see patients with the pediatric team before a formal adult team is established. Once the adult team is established, within a reasonable period of time, it will offer its own clinic for the patients who are being transferred. There will be a period of time where the pediatric team will attend the adult team clinics and team meetings. This, of course, will vary depending upon the logistics involved. For a program to be an effective "transition" and not merely "transfer" program there must be ongoing contact between the two teams.

Once the two teams have established a trust in each other these meetings will be less frequent. A monthly Transition Conference, that is a joint case conference on patients being transferred should continue to occur. At this conference both teams will discuss patients who are being prepared for transfer.

Because quality of care is such an important issue for both teams, a monthly Consensus Management Conference is a useful vehicle for establishing guidelines for care and discussing care management issues. Annually, as a part of this conference, major care management issues are discussed and treatment protocols formulated for distribution to both teams. An example from the cystic fibrosis transition program of a product that evolved out of this type of meeting is a protocol on management of hemoptysis, pneumothorax, and distal intestinal obstructive syndrome.

## Written Transfer of Information

To maintain a programmatic consistency, certain features of the program should be preserved as a written record for communication between the teams and with patients.

• Patient Transmittal Form to transfer pertinent information about each patient to be transferred. (See Medical Summary Transfer Form, page 45).

• Coverage Schedule to inform patients and families about whom to call for problems and emergencies when in transition from one unit to the other.

- Patient's list of the appropriate numbers to call and a coverage schedule to be posted for both teams.

- Inter-office Memorandum to clarify issues and maintain as a reference for futur~ considerations.

# Medical Summary Transfer Form

Name_____

Birthdate_____ Age at Diagnosis_____

Presentation (MI, Bronchitis, FTT, etc.)_____

SWEAT
TESTS_____

_____

OtherTests_____

_____

Family(structure,siblings,CysticFibrosis,problems) _____

_____

Occupation/Education _____

Allergies _____

Previous Complications _____

Previous Surgery _____

Hospitalizations Previous Year _____

Last S-K Score _____          Last Brasfield Score_____

Last Sputum C/S _____

Copies of Laboratory Reports Attached (most recent):

CXR _____ PFT_____CBC_____Biochemical Profile_____U/A_____Other_____

Course over last year, special problems, "Things you out to know"_____

_____

_____

_____

- Patient Records to be transferred from the pediatric unit to the adult team, which usually will require a patient release form. The teams will have to decide what aspects of the record will be necessary for transfer such as annual summaries, etc.

- Statistical Summaries to be prepared annually by both teams. These data will be important to share for program planning and evaluation purposes.The elements of the summaries will vary according to the nature of the disease served by the program. See Program Statistics Form     (page 48) for an example.

- Brochures and Letterheads to reference each other's programs are helpful sources of communication to patients and families and demonstrate the relationship of the two programs. An example of this in the cystic fibrosis transition program is the letterhead used by the pediatric team that also includes the location of the adult team and the names of the adult team members. Additionally, the pediatric team brochure lists the adult team contact person and phone number.

# Program Statistics Form

## PERIOD JULY 1, 19____ - JUNE 30, 19_

TOTAL # PATIENTS_____
# PATIENTS IN TRANSITION PROGRAM_____
TOTAL # ADMISSIONS

| MULTIPLE ADMISSIONS | #PATIENTS | #ADMISSIONS |
|---|---|---|
| (Please list the number of patients with each number of multiple admissions, e.g., 2 patients with 3 admissions, etc.) | _____ | _____ |
| | _____ | _____ |
| | _____ | _____ |
| | _____ | _____ |

| | |
|---|---|
| AVERAGE LENGTH OF STAY | _____ |
| MEAN LENGTH OF STAY | _____ |
| AVERAGE # PATIENTS IN HOUSE | _____ |
| AVERAGE # DAYS BETWEEN ADMISSIONS | _____ |

**PAYER MIX**

| | ACTUAL | | REGISTERED IN PROGRAM | |
|---|---|---|---|---|
| | # | % | # | % |
| MA | _____ | _____ | _____ | _____ |
| MC | _____ | _____ | _____ | _____ |
| BC | _____ | _____ | _____ | _____ |
| CF | _____ | _____ | _____ | _____ |
| HMO | _____ | _____ | _____ | _____ |
| COMM | _____ | _____ | _____ | _____ |

Building Inter--team Relations

Two types of activities are needed to build connections and a good working relationship between the pediatric and adult care teams. First, feelings and attitudes about each other must be addressed. Then practical problem solvings strategies need to be developed so that the two teams can develop a smooth way of functioning together.

Feelings and Attitudes

- Consider having the first meeting in a "neutral" place.

- Have both team leaders present the concept of the program.

- Plan for regular, periodic meetings during the first year or two to discuss issues of concern to team members. This should be a mandatory meeting for all team members and clinical activities should be planned accordingly. There should be no reason or excuse for a disgruntled team member not to come to these meetings to resolve problems.

- Let team members know that negative concerns can be brought up at the meetings. It will be helpful for team leaders to model this behavior. If a team member feels very uncomfortable about bringing up a particular issue, then the team leader may do it.

- It is important to share one's feelings of loss, worry and concern about the transfer of patients so that the other team can understand both perspectives.. This sharing process must, however, be done carefully, to avoid it becoming a destructive force. There are a few guidelines (see below) that can help although it may be useful to have an outside consultant to make sure this process is productive. Consultants may be available from mental health departments in your institution, from university faculty in social and industrial psychology, business administration, educational psychology, etc. If you decide to try this on your own, use the following guidelines:

Guidelines for Sharing Feelings and Attitudes

- Use "1" statements only -- I feel sad about not seeing my favorite family any more. I feel that this family needed more contact with your social worker during the last hospitalization. I feel like I've entrusted my children to you, and I don't even know you well enough to be sure you'll do a good job.

- Share good feelings as well as bad

- Share your feelings and then try to explain how the other team might feel about the same issue

Procedures for Inter-team Problem Solving

At each inter-team meeting, you can use this procedure to structure the problen. solving process. Assign one person to facilitate the meeting. It is helpful if this person has a blackboard or "flip charts" to record the process. In addition, assign one person to be the recorder so that all decisions are recorded and written copies distributed to all members of each team.

Step 1    Have each person write down the following:

A.  Goals of the project (Goal statements should be very broad--see Self--Assessment   on page 7 for examples).

B.  Things that are going well toward meeting each goal
C.  Problems that are preventing meeting each goal

Step 2    Go around the room asking each person to share two goals. This is done quickly, with no discussion or elaboration. Write these on the board. If there are any remaining goals, solicit them.

Step 3    Discuss any disagreements in project goals and develop a concensus.

Step 4    Take each goal and elicit things that are going well and problem areas for each goal.

Step 5    Take each problem area and spend a short time (5 minutes, tops) brainstorming about the sources and possible solutions to each problem.

Step  6    After brainstorming for each problem, assign a person or persons responsible for developing the solutions for each. Give a deadline for completion of the task and a way to report results back to the total group. Be sure that those responsible have the power to develop or implement their solutions or have the support of those that do.

Step 7    Send a written memo of all actions taken in the meeting to all team members.

An example of the results of this process are:

*Goal* -- Smooth transfer of patients' care to adult team

.

*Problem* -- Patients are not sure which team to call with night and evening emergencies. When they call the adult team's hospital, there is no one designated to take call.

*Persons Responsible* -- Team physicians

50

*Task* -- Develop on-call schedule, see that operator has it, ask team nurse to develop and send brochure on this issue to all new patients.

*Deadline* -- Two weeks

# CONCLUSION

Congratulations! You have at least read through this entire manual. We hope you have stopped along the way to use the self-assessment exercises, as needed, and are now headed in the right direction. You may want to refer back to this manual frequently during your efforts. Developing an adult care team and developing a process of transition are challenging tasks. They are also worthwhile tasks. The steps you take will vary in their difficulty and you will undoubtedly find some steps you need to take that we have not included. Each project will be different. We hope our manual has at least given you a basic outline for approaching this task.

Remember, transition is an issue that will tax your minds and your hearts as you tackle it. Pay attention to both, if you are to succeed.