

# Helping Parental Caregivers and Mental Health Consumers Cope With Parental Aging and Loss

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As persons with severe and persistent mental illness age, large numbers continue to live with their elderly parents or receive substantial social and economic support from them. Prospective studies suggest that when caregivers die, individuals with mental illness experience housing disruptions and potentially traumatic transitions. This paper describes the scope of the problem and addresses pragmatic and psychological issues involved in preparing both caregivers and patients for parental aging and eventual loss. It outlines the practitioner's role in helping patients and families overcome specific psychological barriers to planning for continuing care management, appropriate residential alternatives for patients, and their timely placement. The discussion emphasizes helping patients control their own futures by proactively ensuring resources for maintaining or improving their quality of life. The Planned Lifetime Assistance Network (PLAN), now available in some states through the National Alliance for the Mentally Ill, is described. PLAN, and similar organizations, provide lifetime assistance to disabled individuals whose parents or other family members are deceased or no longer able to provide care. (*Psychiatric Services* 50:369–375, 1999)

As the era of deinstitutionalization matures, we are beginning to see a generation of cognitively and functionally impaired consumers who are growing older in the community rather than in the hospital. These individuals are highly dependent on sheltered environments and natural support systems. Many live with their families, particularly with elderly parents.

The literature on the issues and problems of elderly caregivers of persons with severe mental illness is limited (1–4). Somewhat more research on aging parents is available in the field of developmental disabilities

(5–7). Although this literature provides valuable insights that are relevant to the field of mental illness, caution is advised in generalizing across disabilities.

Some evidence exists that parents of persons with psychiatric disabilities may experience more severe difficulties than parents of individuals with mental retardation. Research suggests that relationships are more conflicted and the behaviors of offspring more disruptive, and that support systems for caregivers of adults with mental illness are less available, with fewer resources for substitute caregiving in the future.

For example, Greenberg and his associates (8) found that older mothers of adults with mental illness reported higher levels of subjective burden, lower levels of psychological well-being, poorer relationships with their offspring, and greater behavioral problems of their offspring than did older mothers of developmentally disabled offspring. Pruchno and associates (9) similarly found that aging mothers of adults with schizophrenia manifested significantly lower levels of well-being and higher levels of distress than did mothers of developmentally disabled children. Seltzer and colleagues (10) have suggested that feeling blamed by professionals for the illness of their offspring has been a source of family burden for aging parents of adults with mental illness that is not experienced by parents of adults with mental retardation.

Further comparisons have indicated that mothers of adults with mental illness have significantly smaller support networks and are more dependent on social support for their psychological well-being than are mothers of adults with developmental disabilities (11). The investigators attributed this finding to the relatively stable coping patterns that families develop over the lifetime of offspring with mental retardation; mental illness develops later in life, often presents unexpected challenges, and occurs in cyclical and sometimes unpredictable patterns.

Evidence from the field of developmental disabilities indicates that many older parents have not planned

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for the time when they cannot assume the burden of caregiving (12). They operate on a philosophy of "one day at a time" and face this eventuality with a great deal of indecision and ambivalence. Comparative studies indicate that failure to plan is also common among parents of mentally ill offspring (13). Moreover, little attention has been given to preparing this group of dependent disabled adults for the growing frailty and eventual death of family members or other caring persons who have been highly significant in their lives. This paper deals with pragmatic and psychological issues that may be encountered by service providers who work with this group of aging patients and their families.



### **Scope of the problem**

First, how widespread is the problem? Unfortunately, we have no sound national database on community-based residential arrangements of persons with severe mental illness and characteristics of their caregivers. Some research suggests that co-residential family caregiving may vary by ethnicity. A New Jersey study indicated that approximately 32 percent of white American families with a family member with mental illness resided with that family member, in contrast to 60 percent of African-American families and 75 percent of Hispanic-American families (14). Even higher percentages are suggested among Asian-American families (15).

A survey of a nationally representative sample of 1,401 member families of the National Alliance for the Mentally Ill (NAMI), a predominantly white middle-class organization, indicated that 42 percent of mentally ill relatives were living with their families, and 11.2 percent with other relatives (16). Only 14 percent were living in some type of supervised community residence. Sixty-three percent of the consumers were male, and the average age of the male consumers was 37 years. Female consumers were older. Among all consumers, 88 percent had never married or were currently single, and almost 90 percent had a diagnosis of schizophrenia or bipolar disorder.

Respondents were for the most part older women, typically mothers of the consumers. In this survey, as in previous studies of NAMI members (4), the typical picture was of a son entering middle age with a caregiver mother or parents in their sixties to eighties.

In New York State, a study of patients who met criteria for severe and persistent mental illness found that more than half resided in household settings, the majority with relatives (17). It was estimated that from 13,000 to 49,600 adults with severe mental illness lived with one or both parents during a four-year period

  
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(1990–1994). Most of these psychiatrically disabled adults living with their parents were at least 25 years old (84 percent); 65 percent were over 30 years old, and 12 percent were over 50. Clearly, many caregiving parents are now or soon will be a part of the geriatric population and approaching the end of their lives.

The presumption may well be that if an elderly caregiver and an elderly dependent are able to live together, they have reached some accommodation or indeed enjoy a relationship that is mutually beneficial. Some studies have found that caregiving brings gratification to aging parents because their offspring provide com-

panionship and help (18,19). However, other research has found that older parents feel significantly burdened by their responsibilities and that all have anxieties about the future of their mentally ill adult child (1–4).

Regardless of gratification or burden, reports of families' worries about the future are found throughout the caregiving literature. A synthesis of the research on parents of adults with developmental disabilities as well as adults with severe mental illness indicates that all aging caregivers suffer similar anxieties about "when I am gone" (20). Typically parents worry about adequate housing, financial management, social outlets, and general quality of life. Parents of consumers with severe mental illness worry about medication monitoring and assurance of treatment and continuity of care. Many are afraid to trust ongoing case management to a system that, under increasing funding constraints and the disincentives of capitation, may be all too happy to ignore dropouts or consumers who fail to keep appointments. Without their vigilance, parents fear that their loved ones will stop taking medications and relapse, or worse, become lost to the treatment system.

Many families try to plan ahead for numerous contingencies. Parents with modest resources investigate special-needs trusts in order to leave just enough for their relatives to have a few extras, such as clothing, a haircut, or an occasional movie, without imperiling the relatives' meager federal entitlements and particularly their Medicaid benefits. Parents may enroll in plans that facilitate continuous case management and some level of social relationships. They may attempt to organize families with mutual interests into developing and possibly administering such plans. They may try to develop and link funded plans with professional mental health agencies to ensure continuing treatment, rehabilitation, and housing for their disabled loved ones.

Some parents can depend on their other children to help a disabled adult sibling, but many cannot. Most siblings have their work and other re-

sponsibilities, including mates and children of their own, and are unable to invest time and energy with the same devotion as their parents. Moreover, research suggests that siblings of mentally ill persons may experience heavy psychological costs that sometimes militate against the caregiving role (21).

An important study comparing the siblings of mentally retarded and mentally ill adults found they were at opposite poles in their assessments of the experience of growing up (10). Living with a sibling with mental retardation tended to evoke positive feelings, and respondents' well-being in adulthood was predicted by feelings of psychological intimacy with their impaired sibling. Living with a sibling with mental illness tended to evoke negative feelings, and respondents' well-being was predicted by feelings of psychological distance from the impaired sibling.

This extremely important difference has strong implications for social policy. Although some individuals feel very close to their mentally ill siblings, these research findings suggest that in the main, reliance on siblings for caregiving and case management of persons with mental illness cannot always be considered a realistic option.

Moreover, these anxieties are not restricted to disabled adults who live at home. Although concern may be greatest in these situations, family caregivers play many important roles in the lives of their relatives who live elsewhere. They find services for their ill relative, monitor their quality, provide social and emotional support, and serve as a last resort when the system fails (22). Even when housing and supervision are provided by the mental health system, research indicates that parents continue to provide companionship and financial aid, supplementing meager resources with food, clothing, and other necessities. Parents are often the major source of security and psychological sustenance for consumers whose social as well as clinical support may be contingent on the continued funding of the programs that serve them. These roles must be shifted to someone else when parents

die—and even before that, when they become too frail to fulfill these supportive obligations.

### **The practitioner's role**

How can professionals work with families to resolve both practical and psychological issues related to preparation for a caregiver's decline and eventual death? Practical issues relate to financial, residential, and treatment arrangements for the surviving consumer. Psychological issues are much more difficult and wide ranging. At a minimum they may involve resistance and denial of family members who are unwilling to deal with issues of mortality, as well as the



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clinician's own inclination to avoid such burdensome topics. Some families purportedly are unwilling to let go, and separation may be an issue for clinical intervention. Some researchers have found that the demands of caregiving over many years have so demoralized families that they simply cannot plan for the future without professional urging and help (13).

In many cases the issue of substitute caregivers has periodically been considered by families, but typically without discussion or resolution. The question of whether to continue with familial living arrangements or place the consumer in a community program or a board-and-care home pos-

es a dilemma whose resolution depends on objective factors as well as psychodynamic needs. Much, of course, depends on the availability of alternative residential arrangements and on their quality, appropriateness, and willingness to accept the consumer in question. Even more may depend on the consumer's willingness to leave home and accept what is available. Many individuals with severe deficits of schizophrenia or dementia, who obviously cannot maintain themselves without help, are obdurate in their refusal to leave the known environment.

When it is clear that there may be a loss of current caregivers, the individual practitioner or service provider should work with the family and client to integrate psychological and pragmatic preparations for an important life change. The first issue to address is acknowledgment of the need for future long-range planning and open recognition of all the emotional and practical issues involved in planning. Practitioners may need to work with the parents and other family members on their separation anxieties, fears, denial, and other impediments to action-oriented planning to cope with a dreaded but foreseeable event.

Simultaneous work may be necessary with the consumer on recognition and anticipatory processing of loss. The loss will have different forms and salience not only as a function of the degree of bonding and specific relationship of the client and caregiver, but also as a function of the client's level of cognitive and affective impairment. Practitioners must then work toward developing the framework for all family members to engage in a step-by-step planning process and must be able to bring together and integrate the external resources required for the plan. Ideally, this is a team process, involving clinical, human resources, social services, and legal expertise.

### ***Working with the aging caregiver***

Unfortunately, few clinicians receive adequate geriatric training, particularly about resources available to help aging persons who are also caregivers. Elderly adults are generally

experiencing many losses in life, including meaningful work, death of relatives and friends, and declining health. These losses take their toll and make it difficult for them to cope with the additional stresses of caregiving. Parents of disabled children also have the objective burdens of lifelong care and, unlike other older parents, have never finished the task of childrearing. Parents sometimes delay planning for their disabled relatives so long that they become too frail to address the issue. Both consumers and aging caregivers may struggle for years, enduring a poor quality of life because the parent no longer has the energy to work out alternative arrangements (13).

Providers need to know the service system for the elderly population and how it might be used to solve some of the problems of aging caregivers. The Older Americans Act of 1965 provides many programs for the elderly through the Area Agencies on Aging in all parts of the country. In 1992 an amendment to this act called directly for provision of services to "older individuals who provide uncompensated care to their adult children with disabilities, or counseling to assist such older individuals with permanency planning for such children" (23). It is vital that the mental health service system establish collaborative relationships with the service system on aging and the local department of social services to discover and utilize needed resources.

### *Psychological dilemmas of caregivers*

Helping parents prepare for a relative's care when they can no longer take responsibility requires much sensitivity and understanding. Practitioners must be able to take the perspective of parents whose anxieties are so high that they may resist making appropriate plans for their relative. It is easy to be impatient and critical about behaviors that seem to connote denial, overprotectiveness, or incompetence.

In actuality, few families deny the importance of making plans for the future. Research indicates that family members agonize a great deal over

what will happen to their relative when they are gone (3). A survey of NAMI families in 1993 revealed that "what will happen to my relative when I am gone" was the greatest source of psychological pain for 74 percent of the respondents (24). Some families envision their relatives being lonely, miserable, and neglected when parents no longer take responsibility. They share the anxiety that most people feel in contemplating their eventual mortality, together with additional worries due to their child's dependency (Hatfield AB, unpublished research, 1992).

Sometimes an interdependency exists between caregiver and care recipient that serves the needs of both (18,19). They provide companionship for each other, share household chores, and supplement each other's finances. It is difficult for parents to envision any plan in which their loved one's needs are as well served as they have been in the parental home. Parents feel that over the years they have developed strategies for handling a great number of unique situations that others will not be able to handle as well. Parents feel irreplaceable in many ways. No one will care as much or understand as well. They fear that with their loss, the well-being of their disabled child will be seriously compromised (Hatfield AB, unpublished research, 1992).

Some parents have difficulty accepting the fact that they are reaching the end of their ability to help their disabled child lead a more fulfilling life. They still agonize over "what might have been" and want to maintain a protective environment to facilitate the longed-for remission. Others want more time to help their relative overcome behaviors that might not be readily tolerated in the world outside the family. Many parents have difficulty planning for the future because the needs, behavioral symptoms, and general level of functioning of the disabled individual have undergone frequent or episodic changes, and they cannot anticipate future caregiving needs. The service system also tends to go through frequent changes, making it difficult for families to know what services can be

counted on in the future. They tend to put off making plans until situations become more certain.

Service providers need to understand how stressful this contemplated separation is for parents and consumers, and they need to be prepared to offer considerable reassurance and support. The practitioner would do well to open a discussion by describing some of these concerns, normalizing from the beginning some typical reactions to the idea of a caregiver's death and the fears surrounding the issue. Caregivers may react by indicating which concerns do not apply to them and which might apply, suggesting areas of potential denial and the pacing of the discussion. This exchange will set the stage and establish the level for dealing with a threatening subject.

The practitioner may want to phase in a series of meetings, dealing separately with the caregiver's concerns and the patient's concerns and then bringing together the caregiver, patient, other family members, supportive friends, and possibly other experts to develop long-range plans for the patient's future.

### *Working with the patient or consumer*

Preparing patients for the time when parents are elderly and eventually die poses significant challenges. It is not evident in the literature on serious mental illness that much attention has been given to this critical issue. Very little is known about the way that consumers anticipate this eventuality in their lives or how well they make the transitions that follow.

Consumers should be made aware of the developmental changes in the lives of their family members as time passes and their own lives change. Parents and providers need to help consumers understand how the aging process is changing their parents and decreasing the role that parents play in their lives. Parents tend to avoid talking about this topic because they feel it will be stressful and evoke anxieties. At appropriate times it may be up to practitioners to take up these issues with their patients as a means of avoiding even greater stress in the long run.



The aging of parents may provide opportunities for consumers' growth. They may come to recognize the need to do more for themselves and to be helpful to parents who have increasing needs (18,19). It is important to take advantage of this potential for more normalizing relationships with elderly parents.

Consumers should not be unnecessarily shielded from normal life experiences with illness, frailty, and the death of relatives and friends. They should have experiences with customary responses to death, such as memorial services and burials, long before their parents become ill and die. They need opportunities to discuss these experiences with someone they trust and work through any difficulties that emerge.

Situations will vary depending on whether the patient has an ongoing psychotherapist or is primarily working with a case manager. In some situations, the case manager may be called on to arrange a meeting or series of meetings to deal with the prospective disability of an aging family member who has been the one stable person in the client's life. Case managers need some training in potential psychological reactions to the prospect of loss and of substantive life changes. All patients have specific types of relational ties to their parents, both positive and negative. The emotions connected with their loss are likely to be a function of two factors: the valence and intensity of these ties and also the capacity for affective response, which is linked to the illness. Some patients may engage in anticipatory grieving, but others may respond with blunted affect. They may be in denial or may simply be unable to conceptualize a change in the known situation.

The most important and clinically useful approach is to begin with the linked statements that the parents are growing old, and it is a good idea to plan for how the patient's needs will be met after they are gone. This reassurance provides a cushion for the potential traumatic impact of the fantasy of imminent deprivation. A tearful reaction to the prospective death of a loved one is likely to be accompanied by immediate fear of

abandonment. These individuals are in an intrinsic dependency status, and in many cases, the first reaction to the thought of losing a caregiver is "What will happen to me?"

The practitioner's assumption must be that the patient will respond with anxiety about a now-ambiguous future. It may be helpful again to normalize this reaction, to indicate that in addition to sadness at the loss of a loved one, anyone in this situation would be concerned about the changes in one's life. Many people

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would fear that they might lose housing, money for food or cigarettes, or someone to take care of their needs. The purpose of this discussion is to develop a plan that will guarantee that the future will be taken care of. The practitioner may explain the planning process and who will be involved, soliciting the patient's input on potential participants. The emphasis should be that this proactive planning will give the patient some control over his or her quality of life and well-being after the caregivers are gone.

Other unanticipated psychological issues may arise. For example, parents must often make disparate financial arrangements for mentally ill children and their siblings. An estate may be evenly distributed, but the siblings will have free access to their inheritance before or after probate, while the sibling with mental illness will be subject to the provisions of a trust and executor. Often siblings can be left substantially larger sums than the mentally ill adult, whose portion is geared to the maximum permitted by disability entitlements. Unable to understand the legal aspects, patients may view an inequitable distribution of parental assets as proof that they are unloved or valued less than their siblings.

In discussing the inheritance situation, the clinician may have to enlist the help of an attorney, financial planner, or other professional to explain the implications of the inheritance arrangements, not only to the patient but to the family as a whole. It must be made clear to the patient that if the distribution seems inequitable or if direct access to assets is not provided, these steps are taken to protect the patient's interests, not to strip the patient of his or her patrimony. The whole point of the planning process is to make the person feel secure about the future.

### **Making practical plans**

In meetings with service providers, parents need to include others in the family who are likely to be affected by care decisions in the planning process. This means the consumer, the siblings, and other friends or relatives who play some part in the consumer's life. Parents cannot take for granted that someone will necessarily step in when they are gone. These decisions must be worked out well ahead of time, with appropriate financial planning to ensure that the consumer's needs will be met without causing a drain on other members of the family.

If no alternative caregivers can be found among friends or relatives, replacement for the services that parents have been providing will usually be sought in community programs. Families may worry about the ade-

quacy of these programs and the resistance of their relative. Transitions to the care of others should be planned ahead and should occur as gradually as possible. They should be initiated when parents are still able to provide support in the process (25).

Planning residential placement for a person who has been living at home may be especially difficult. Research by Smith and coworkers (6,7) has shown that parents of developmentally disabled adults are often highly reluctant to take this crucial step. The problem also appears to be burdensome for families coping with mental illness. The options are often not attractive, and the consumer's resistance may be high. Parents may initially agree to outside placement and then balk at the reality. Providers may need to deal with the various reasons that parental caregivers resist or change their minds. Having actually viewed the available options, they may feel guilty about placing their relative in a less attractive, less safe environment or distrustful of residential staff who seem young and inexperienced. They may feel unable to cope with their loved one's reluctance or refusal to move, or they may feel a keen sense of loss at no longer being needed.

Providers should help parents and consumers resolve these issues and should also work with parents to ensure that others provide the range of services the parents have been providing. This process may involve money management, cleaning and laundry, shopping and cooking, transportation, medication management, and more. Parents will likely be less anxious about separation if they know that dependable ways have been established for meeting all these needs.

Some private organizations are emerging across the country to provide lifetime assistance to disabled individuals whose parents or other family members are deceased or no longer able to provide care. The agencies monitor the care of these individuals, respond to crises, and help in many ways. The Planned Lifetime Assistance Network (PLAN), now available in various states through NAMI, is one such example. Parents

pay for these services through their personal resources or trust arrangements.

According to *NAMI Facts*, an eight-page document available from the NAMI office (200 North Glebe Road, Arlington, Virginia 22203-3754), "PLAN programs were developed to meet the needs of families who are actively planning the future of an adult child with a disability. The mission of these independent, not-for-profit programs is to help families develop a future-care plan, establish the resources, and identify the person(s) or program(s) responsible for carrying out the plan. Most PLAN programs also provide current services that relieve parents of part of the daily burden of care." The document includes a list of state PLAN offices indicating the population and geography served together with a description of services. Continuously updated materials may be accessed by searching for PLAN on NAMI's Web site (<http://www.nami.org>).

It is clear that not all families can afford to participate in PLAN or have enough resources to establish special-needs trusts that will not jeopardize entitlements. A lack of resources does not mean that less affluent consumers will be ignored when their parents die. In the public sector, many states are now providing variations of the Program for Assertive Community Treatment developed in Wisconsin (26). Assertive community treatment teams have a well-established track record in deterring relapse, teaching skills essential for community survival, and allowing consumers to live as independently as possible. It is one of the most empirically validated psychosocial interventions for persons with severe mental illness. Intensive case management teams try to fulfill at least some of the functions addressed by assertive community treatment teams.

Some private agencies or managed care plans now provide private case management that may be similar to services provided by PLAN. However, because of its development by and affiliation with advocacy groups in many states, PLAN is an accepted mechanism for parents to guide and

control the structure of services to their loved ones. Parents who participate in PLAN will presumably feel more assured that their loved ones will not be vulnerable to the changing funding patterns of the public sector or unexpected increases in service costs. Nevertheless, many advocates feel that future planning should remain a function of the service delivery system and should become an integral component of psychiatric practice with long-term patients with severe mental illness.

## Conclusions

With the graying of the deinstitutionalized population, more attention must be directed toward helping older consumers cope with life changes due to the aging and eventual death of parents or other elderly caregivers. Considerable research is needed to determine how consumers anticipate and cope with these end-of-life issues. Information is needed on the types of services that consumers require to make the necessary transitions at this period in their lives, what resources are available, and what kinds of interventions prove most helpful.

It is equally important to study the family dilemma as parents enter this critical time in their lives. What are the practical and psychological barriers that must be overcome? What policy changes are needed to ensure that consumers handle the loss of their parents and attendant adjustments without undue trauma?

Social policies and clinical planning are clearly needed. Although we are seeing more research on aging parents of persons with disabilities, unfortunately much of our knowledge is derived from convenience samples that, no matter how carefully drawn, can give us only selective and sometimes inconsistent fragments of the total picture (20). We need more studies of the type initiated by New York State on projected housing disruptions among persons with mental disabilities (17). Essential are good national statistics on residential patterns and caregiving characteristics by type of disability, relationship, and age of the disabled persons and their caregivers, resources

for alternative caregiving, projections of housing needs, and plans for the future.

This paper has dealt with pragmatic issues involved in planning and has offered some practical suggestions for clinicians. We have also pointed out psychological issues of separation, loss, and anticipatory grieving. It is difficult to prepare persons with severe mental illness for existential stressors and naturally traumatic life events without evoking undue disturbance. Yet in some cases it is possible that this preparation may facilitate a clinical breakthrough. By suggesting to patients that they are capable of dealing with predictable disruptions and prospective pain, they are held to a higher standard of rationality and responsibility. By involving them in highly specific long-range planning, they become invested in controlling their own future.

In the process of planning, it is important to enlist the aid of as many human resources as possible. The purpose is to expand the patient's potential support system, linking relatives, friends, and professionals in a network of care. Finally, whenever possible, we suggest linking families with advocacy groups. It is hoped that this linkage will generate more community programs and resources to provide an alternative to parental caregiving and facilitate greater independence and growth. ♦

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