SELF-NEGLECT: A PRACTITIONER'S VIEW

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Older people who neglect their needs for nutrition, hygiene, financial solvency, medical care, or adequate shelter do so for reasons as varied as there are human predicaments. Some people have always neglected themselves in one or more of these areas, coming to professional attention in old age simply because they have attained the status "elderly" and now qualify for protective programs. Others took good care of themselves all their lives and now through the strains of memory loss, illness, poverty, or the deaths of loved ones are losing their ability to maintain their previous quality of life. Still others choose to live on the edge of social conventions or literally on the edge of the wilderness, with the result that they accept risks to their health and safety deemed neglectful by others.

The key difference between services for protecting children and those for adults is that mentally competent adults who do not wish to be protected have the right to refuse all assistance. When self-neglect is severe, this right to self-determination places relatives and professionals in heartbreaking dilemmas. How strenuously should they try to persuade such a person to accept help? Should they attempt to enforce safety measures by threatening to abandon the person entirely if there is no cooperation? Should they try to compel acceptance of unwanted services by bribing the person with desired rewards or benefits?

This legal duty to respect older people's right to run their own lives may become equivalent to witnessing slow suicide, unless acceptable interventions are found. It is important to understand the dynamics of individual and family problems that lead to self-neglect in order to develop effective interventions. The following are some of the typical situations in which elderly people neglect their health and welfare and some interventions that have proven successful in those situations.

Loss of the Will To Live

Ordinarily, motivation for self-care arises from motivation for life. In some cases, self-neglect is best understood as disaffection from life, a loss of the will to live. Interventions which provide something to live for can be effective in these instances, but devising them is not easy. When older people are socially or geographically isolated, or too frail to participate in volunteer programs, meaningful activities may be in short supply. Some may have lost previously satisfying pursuits through sensory losses, such as no longer seeing well enough to paint or no longer hearing well enough to play the piano.

Depression may be at the heart of someone's self-neglect. The person's view of the world may be obscured by tunnel vision, with their depression blocking out fresh ideas for reviving their spirit for life. In these situations, the temporary use of anti-depressant medication may widen their vision and help mobilize the very changes which would broaden the scope of their possibilities. For some, knowing that the medication can be stopped once this revival is achieved may make this remedy tolerable. Others may need to learn how many millions of people use these medications at some point in their lives.

Grief is another major cause

of self-neglect. Some people let their lives dwindle during a bereavement and then find themselves stuck in a state of malaise long after their grief should have subsided. Caught in a self-defeating cycle, they lack the will to get out and do things and then must face the deadening sameness of a daily life without involvements. This monotony further dampens their drive to keep up with friendships and activities, leading to still less motivation to take care of themselves.

Asking the question, "What would make life worth living for you?" is often a helpful starting point. Some people respond with clear statements about wishing they could be useful or that they had a pet or a garden to look after. Their replies are full of hints for ways to re-awaken their spirit for life. Others become stymied by this question because they have lost faith in themselves, in God, or in other people. In these instances, it may be helpful to venture a few specific ideas, even if the person vehemently rejects these options as unsuitable or unrealistic.

In their very vehemence, some people reveal themselves. Listening carefully while someone bursts forth with negative feelings may yield clues. Residual shreds of enthusiasm may emerge as one option after another is rejected: "I don't want to sit all day with a bunch of old duds at day care, not doing anything, not learning anything, just existing." Doing and learning may be the key to any intervention created for people appalled by the absence of activity and novelty in their lives.

No one can presume to know what would make life worth living for someone else. Without such dialogue, relatives and professionals who still have full health and freedom can easily overlook a solution that would mean a great deal to someone living in reduced circumstances. Small changes often lead to large rewards in a life that has been devoid of provocation or stimulation. For instance, a woman who never leaves her apartment may find that having help getting down to the lobby once a week to see a bit of the world may give her something to look forward to and a reason to start taking her blood pressure medication more faithfully.

This process of challenging older people to describe what would help inspire their self-care is both respectful and potentially effective. But responding to the clues that emerge in this fashion requires creativity. People who neglect themselves already tend to fall outside the range of standard solutions or they would not be so difficult to assist. Professionals may need to spend considerable time with such individuals, trying out one idea after another. Family members can sometimes hasten the process by providing information as to what used to give their relative something to live for. Generally, however, there is no substitute for spending time with the person and passing ideas back and forth until something sparks.

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Violating Medical Restrictions

When someone refuses to heed vital medical recommendations, loss of the will to live may be the central reason. At other times, the person's defiance may stem from different causes. Confronting the person's self-neglect head on sometimes unlocks these other feelings: "You're eating cookies even though your blood sugar is sky-high. You're killing yourself by inches." Speaking the truth of someone's actions out loud may startle the person into expressing the underpinnings of their choices: "I don't care. Food is my best friend, the only good thing I could ever count on."

Underneath anger at dietary restrictions may lie rage at the perceived deprivations of a lifetime. Until such anger is released, discussions may circle around, going nowhere. Letting someone express this rage directly may clear the way for more constructive talking about self-care and the risks of continuing to ignore necessary restrictions. Those who have never been able to control their eating often need referrals for help with their addictive behavior and may respond gratefully to the recognition that their problem is deeper than simple "non-compliance."

Some older people go against medical advice as a rebellious act, a way to assert personal freedom within con-

straining circumstances. Life can seem particularly devoid of satisfactions when diet is restricted, mobility is limited, smoking is prohibited, and sexual activity diminished or nonexistent. Breaking through limitations then serves as an act of vitality, a flaunting of risks in exchange for a liberated feeling. The proclamation, "So what? I'm going to be dead soon, anyway," often accompanies defiant puffs on a cigarette and binges of favorite foods. Such people seize upon a sense of entitlement to the last days of life, even if their self-destructive actions decrease their remaining days.

Relatives and friends can often dispense powerful challenges to such disregard for health. A daughter can say, "Mom, when you binge on those salty potato chips, I get scared you'll have a stroke and die. I want you to live for a long time." Similarly, a family member can plead with a loved one to give antidepressant medication a chance, pointing out that the pills may help mobilize the very changes that would lead to real freedom: "Dad, these medicines might give you the energy to quit smoking. If you breathe better, you'll be able to go fishing again." Linking improved self-care with longevity and freedom may wake someone up to the rewards for following medical advice.

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Self-Destruction Through Drugs or Alcohol

When approaching an older person's use of drugs or alcohol, it is important to distinguish between lifelong addiction and recent dependence on drugs or alcohol in response to later life losses. Lifelong addicts are deeply accustomed to blocking out painful feelings. They may never have learned how to tolerate anxiety, boredom, hurt, or frustration. In addition, the extent of their physical addiction may make it dangerous for them to try to stop alcohol or drugs without medical supervision. Hospital-based treatment for chemical dependency, covered by Medicare, is often the best option in these instances.

In contrast, those who have not previously depended upon alcohol or drugs as a means of survival tend to reach old age with a repertoire of coping skills. Having been able to endure life's hardships over the years, they become chemically dependent only after health problems interfere with their strengths or when too many losses occur at once. For instance, studies have shown that caregiving, retirement, death of a spouse, and disfiguring surgeries are the four major causes of alcohol dependence later in life. Receiving help that specifically addresses these issues may prevent the need for in-patient treatment and may set someone on a healthier course for bearing their difficulties.

When a relative refuses to accept help and continues on a self-destructive course, family members may find themselves stuck in the role of rescuer. For example, a daughter may be furious each time she has to give her alcoholic father money for food, yet insist "I can't let him starve to death." One alternative is for the family member to offer to hold a portion of the person's income solely for groceries and to parcel it out week by week. Another is to bring over the groceries, rather than give cash that might be used for alcohol. But such measures do not solve the dilemma of the rescuer role and consequent feelings of futility and anger.

Many people will not accept treatment until family members stop protecting them from the consequences of their addiction. Letting a loved one reach bottom is often essential to breaking through the addicted person's denial of their dependence on drugs or alcohol. Professional guidance in this effort is frequently a family's best recourse, as are support groups which aid the family in practicing "tough love" and setting healthy limits. A caseworker from the state's adult protective services division may also be able to assist with gaining the older person's willingness to enter a chemical dependency treatment program.

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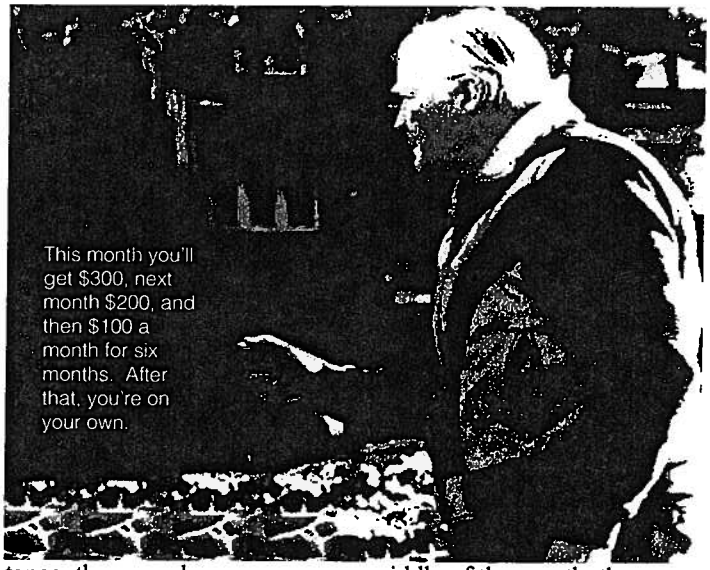
Destructive Entwinement: Parents Who Endure Abuse from Adult Children

Long into later life, some parents go on sacrificing their financial and emotional resources for the sake of a grown son or daughter. They put aside their own needs to the point of harming themselves. Their adult child may plead for help with overdue rent, bills for psychotherapy and associated medications, or projects and investments which are then converted into money for drugs or alcohol. The older parents may vow that this is the "last time" they will be fooled, or persuade themselves that "this time" their son or daughter will accomplish something, only to be repeatedly disappointed.

This pattern may worsen as the years pass, with the older parents feeling ever more fatigued and alarmed. Savings they had intended for their own security may have vanished. As the end of their lives approaches, they may worry how this son or daughter will manage after they are gone. Hoping their protective role will be taken over by one of their other children, they may encounter hostility rather than sympathy.

Siblings in these situations usually resent the brother or sister they view as exploitative. Over the years, their resentment may have deepened each time this person caused their parents distress. Their fruitless attempts to convince their parents to stop wasting money on this sibling may have embittered them toward their parents. Claiming they have been cheated of their future inheritance, they may be angry about what they see as "special treatment," which drained resources that should have been shared equally.



Grasping the magnitude of this accumulated bitterness may come as a blow to older parents. The realization may be especially distressing if it occurs just as they are facing care needs of their own. Their other children may make their assistance conditional: "Mom, we won't take care of you unless you take Billy off your bank account. We're sick of him living off you." The siblings may feel that it is no use helping a parent who will only go on neglecting herself under the guise of being loving and protective.

When older parents allow an addicted son or daughter to move in with them, their Social Security income often ends up paying for the addiction. Lacking funds by the middle of the month, they may omit necessary prescriptions or fail to follow their dietary restrictions. Tensions often mount as bills go unpaid. With inhibitions blurred by drugs or alcohol, the adult child may abuse the parents verbally and physically. Too ashamed to seek help, the parents may then put off their regular visits to the doctor to avoid revealing their bruises. Gradually, the medical problems they have ignored may render them dependent for help on the very person who has been harming them.

Such profoundly entwined situations are difficult to unravel. The parents may feel as afraid as ever to say "no" to their troubled son or daughter when their help is requested. They may insist that they are only being protective, rejecting family members or professionals who try to get them to see the situation another way. Justifying their son or daughter's conduct by blaming others is another common defense used by these weary parents. As they drain funds that would be better spent on their own care, they may insist that no one else understands their loved one as well as they do: "Things just haven't gone well for Billy, and now no one will give him a chance to prove himself." Self-deception of this magnitude is often impenetrable. Some will go to their deaths rather than take a look at their own participation in the destructive patterns. Others may vaguely see that their protection can be damaging but fear that their vulnerable son or daughter will end up living in the street — a fear that may not be totally unfounded.

The best that family members or professionals may be able to do is to propose options and leave behind constructive ideas. In this effort, the key is to avoid a judgmental attitude, which will only arouse the parents' defensiveness and keep them from thinking over these ideas on their own. Gentle prodding with questions is often helpful, so long as the tone is respectful: "Since you're not going to live forever, have you thought

about stopping your help now so you can be there for your son when he gets his life together?" The idea that they can end the financial dependency while continuing to "be there" emotionally may never have occurred to them before. Another is: "Can you see that each time you pay his bills, he can go on denying that alcohol is causing him any problems?" A neutral, informative manner may permit these ideas to be heard.

The parents may need one further concept to inspire change: "Have you thought about the legacy of resentment you are leaving your other children? The more you allow your son to take from you, the more your other children resent him." The idea that the others will want to have nothing to do with their sibling after the parents die is a tragic legacy, precisely what most parents in these situations dread. Once it is made clear to them that this is the legacy they are creating by enduring abuse, some may feel determined to end the destructive dependency before it is too late.

Some parents find themselves ready and willing to set limits, but may feel they are unable to say no in the face of the anger or threats they are likely to encounter. In these instances, having a neutral third party, such as a bank or a representative payee, take control over their finances is often an effective intervention, so long as the parents are prepared for the adjustment period that will ensue as soon as the dependent adult child loses access to the money supply. Giving the son or daughter ample notice may ease the transition, as well as implementing a gradual withdrawal of financial support: "This month you'll get $300, next month $200, and then $100 a month for six months. After that, you're on your own." Warning the parents that there may be a period of acting out and testing the limits may help them abide while their son or daughter slowly attains a more constructive manner of living. Assisting the adult child with referrals to drug and alcohol treatment or mental health counseling may further bolster the parents' endurance as they put an end to the exploitation.

Sensitivity to the power of parental guilt is essential for helping older parents extricate themselves from destructive patterns. Parents in these predicaments tend to be burdened by remorse about errors made earlier in their lives that they fear may account for their son or daughter's lack of success in life. Parents who physically or sexually abused their children or who neglected them due to their own problems with drugs or alcohol may be especially reluctant to talk about the past. A friend or professional who hopes to assist older parents with such painful matters must be prepared to offer a considerable amount of listening. When pent-up feelings and fears are released, the process of sorting them out and making sense of what happened is both time-consuming and complex. When sufficient time is not available, it is preferable to make referrals to other sources of help than to open up the issues and leave them unfinished.

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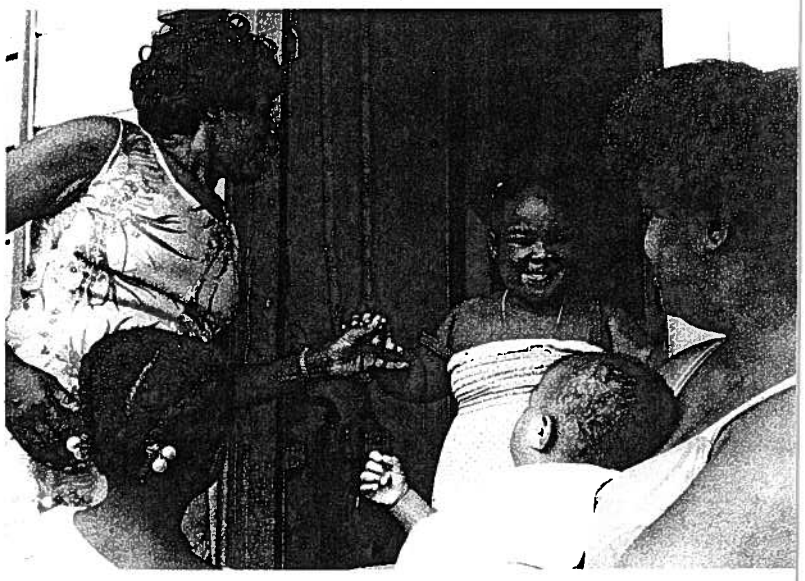
Grandparents Protecting Grandchildren, Neglecting Themselves

As drug and alcohol abuse have become more prevalent in recent decades, increasing numbers of grandparents are taking care of grandchildren whose parents are addicted. The grandparent may move into the household to ensure that the grandchildren have food on the table, or the family may move into the grandparent's residence, having been evicted from their own. In other instances, the grandparent takes over the children's care entirely because the parent has gone to jail, abandoned the children, or the neglect and abuse has become too severe.



Financial problems often become overwhelming in these situations. The addicted parent may be using the AFDC check for drugs or alcohol, leaving the grandparent to try to support everyone's needs on her own income. If the grandparent is still employed, the costs of day care may severely cut into her income. The grandparent may begin to neglect her personal needs in the effort to make ends meet, no longer visiting with friends, filling prescriptions for vital medicines, eating the right foods, or tending to her own health problems.

The child care itself may exceed the grandparent's physical capacities. For example, a woman with severe arthritis in her hands and knees may take a 2-year-old grandchild into her home during the day. Fearing that she might drop the child or be unable to pursue him fast enough to keep him out of

harm's way, she may nevertheless prefer her risky care to that which the child's drug-addicted mother provides when the older grandchildren are at school. The fact that her joints become swollen and painful under the stress of these exertions may be yet another sacrifice that she bears for the child's sake.

In most states, child protection workers and adult protection workers both have insufficient resources to offer these grandparents. Subsidized housing, low-cost day care, grandparent support groups, income supplements, and transportation assistance are examples of the resources which tend to be lacking. Additionally, state regulations may be such that a grandparent who manages to negotiate the paperwork to make her role "official" actually receives less financial support and fewer services than a foster parent who is not a family member. Many grandparents persist in such situations because they see no other options. They live from day to day, trying not to think too far ahead in their quest to provide basic protection to their grandchildren. They feel it is enough to get through each day with the grandchildren adequately fed, clothed, and sheltered, or to stand by as a bodyguard to prevent physical or sexual abuse in the chaotic environment set by the addicted parent. The fact that their health is deteriorating from all the strain and self-sacrifice may be the least of their concerns.

The most useful interventions focus on what the grandparent desires above all else: a better life for the grandchild. In this regard, a professional or family member can start by assisting the grandparent with using existing resources more effectively. For instance, if the grandparent's Social Security check is being used by the addicted parent for alcohol and drugs, the grandparent may be willing to set up a direct-deposit bank account to which the addict does not have access and which is managed by someone outside the family. In this way, the household can be supplied with food and the grandparent's prescriptions can be filled as needed. These changes can be introduced slowly, with the majority of the elder's monthly income gradually going toward groceries, medications, and other necessities.

Helping a grandparent assert herself in this manner may require many discussions emphasizing the long-range benefits: "This way, you'll live a lot longer and your granddaughter will have a grandmother to protect her a lot longer." Pointing out that setting an example of self-care is as important as any other lesson taught to a grandchild may further inspire the elder to bear the strain of taking back control of her finances. Education about addictions may also be helpful, such as through attending Al-Anon meetings. Regular visits from a community volunteer or case manager may further reduce the misuse of funds by adding extra witnesses to what goes on in the household.

In some areas, support groups have begun to assist grandparents in this position. Referring an isolated grandparent to such a group, even if the closest is accessible only by phone, may serve as a vital source of strength. Hearing how others struggle in similar situations may help the grandparent put aside shame and reach out for other kinds of help. Becoming involved in the political effort to improve public benefits for grandparents may help the grandparent feel less powerless about her situation. Exchanging information with other grandparents about day care options, health care clinics, and other resources may markedly expand the grandparent's capacity to go on.

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Eccentricity or Self-Neglect?

There are people who, early in life, reject the typical American lifestyles and choose a style of their own making. There are others who fall into eccentricity gradually, such as by collecting clutter in their houses for years, until their tables and chairs and hallways are filled to the brim. Some people diverge by choosing to live close to nature and dispensing with modern conveniences, maintaining this lifestyle long into their old age. Still others become unusual in response to the aging process, adapting to their physical changes in ways that make sense to them but that appear odd to those around them.

Deciding whether a particular situation warrants intervention and figuring out how far to go with attempts to intervene, takes considerable time and deliberation. Regrettably, caseloads in public agencies tend to be so huge that workers find they cannot invest the amount of forethought and individual attention each case deserves. Instead, they try to make judgments and devise interventions based on the sparse information they can

acquire within their brief time allotments. They are further constrained by laws protecting the right to self-determination and by their individual levels of professional skill.

Regardless of these constraints, pressures to take decisive action may come from several directions at once. A woman's neighbors may repeatedly complain of terrible odors coming from her apartment. A senior housing manager may insist that "something" be done about the rotting garbage that this woman fails to remove from her premises. A nurse from a physician's office may threaten to refuse services if she keeps coming into their waiting room with hygiene so poor that other patients are offended. The local newspaper, tipped off by a frustrated neighbor, may seize upon the story as a way to portray the failure of a public agency to do its duty. No matter how intense these pleas for action, workers may be left with no recourse but persuasion.

Persuading someone to change their chosen lifestyle is not a simple matter, either ethically or practically. The right to self-determination includes the right to exercise bad judgment. Someone may refuse help with removing decomposing piles of magazines from her living room and kitchen, even though the smell of dead mice in the bottom layers of these piles is overwhelming. She may value her magazines more than sanitation or the good will of her landlord and neighbors. Legally, control cannot be taken over someone unless their actions present an immediate danger to themselves or to others. Rotting magazines and bad odors do not constitute an immediate danger to anyone.

Providing concrete information to such people about the nature of the risks they are taking or the consequences of their particular choices is often all professionals and family members can do. In the example above, the woman could be informed that she risks getting sick if she continues to prepare food in her unsanitary kitchen. This is a factual matter, rather than the imposition of another's personal standard of cleanliness. Keeping the provision of information as neutral as possible allows such people to weigh their preferences against clearly depicted consequences.

Regardless of the right to self-determination, there are situations in which eccentricity does turn dangerous. Over time, indifference to the upkeep of one's dwelling or person can become a threat to health and safety. When a chainsmoker is careless with ashes in a house filled with dried-out newspapers, or when someone's skin is covered with infected sores from poor hygiene, death can result from a continuation of their indifference. Self-neglect to this degree often results from, or is worsened by, problems with memory and orientation, but establishing in court that someone is no longer mentally competent is a slow and complex process. In some localities, applying for guardianship of the person may still be the most expedient remedy, while in others the waiting list for guardianship cases is so long that this intervention is too slow.

Another option is to arrange for a friendly visitor from a church, synagogue, or neighborhood volunteer program. There are some instances in which eccentric people accept help when it is rendered in the context of a caring relationship. The visitor gradually establishes rapport and warmth, taking an interest in the elder's dietary needs, hygiene, and medical condition. Over time, the elder may begin to transform the visitor's caring into caring about themselves, as if absorbing the kindness as nutrition for the soul. In one case, a 75-year-old woman explained that she started to take her medication faithfully and to improve her nutrition because she did not want to disappoint her volunteer: "She'd worry about me if I didn't take my pills and eat right."

In many instances, eccentricity is accompanied by aloneness. It is difficult to say whether social isolation produced the eccentricity or the eccentricity caused other people to flee, but the aloneness is usually extreme. No matter what the causal relationship, determining whether the older person is responsive to interest and caring may be the key to devising an effective intervention. It is a rare person who does not respond to consistent and faithful interest, if such alliances can be created.

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Confusing Friendship and Exploitation

Exploitative people posing as friends frequently prey on vulnerable elders (See articles on pp. 62 and 66). Their true numbers will never be known, for the simple reason that their victims generally do not perceive their victimization. Exploiters find their prey in public places, such as fast-food restaurants and bus stops, or in their own apartment buildings and neighborhoods. Lonely older people, those recently bereaved, and those who have lost vision, hearing, or physical mobility become easy targets to the extent that their loneliness, sorrow, or disability becomes visible to these fortune-hunters.

In a typical progression, the exploiter starts a conversation with an older person, finding out that the person lives alone and is having difficulty with household chores and errands. The next move is to offer to do some housecleaning or errands for a few dollars an hour. Once having gained entrance to an elder's life in this manner, the exploiter then builds on the relationship, feigning interest in the elder's circumstances while explaining all about personal troubles of their own. Eventually, the relationship begins to feel to the older person like a friendship.

The next stage tends to evolve slowly, in increments small enough to avoid arousing the older person's suspicion. The exploiter may ask for occasional cash loans or for a few more dollars added to their wages. The bolder ones may ask for "favors," such as borrowing the use of the elder's car or using the elder's credit card with promises to pay when the bill comes. Some get the older person to buy them "gifts" of clothing and jewelry, or to take them out to dinner on a regular basis, all under the guise of friendship: "You're so good to me. What would I do without you?" The older person feels useful and affirmed, glad to be playing an important role in someone's life. The further evolution of these relationships rests in the sense of importance the older person feels. The exploiters know how to take advantage of a lonely person's hunger to matter to someone else or an idle person's yearning for a purpose. The role of protector or benefactor may satisfy a deep need. Time that had been empty or pointless may turn into something meaningful in the hands of someone skilled at playing the part of a grateful recipient.

If challenged at this juncture to explain money given away or purchases made on the exploiter's behalf, the older person may cite all the things this "wonderful" person has done for them in terms of chores and errands. Having lost sight of how the relationship began, the person may see those tasks as kindnesses granted by a friend rather than jobs done by a hired person. If reminded of how recently this "friend" came into their life and how friendships do not normally require so much financial generosity, the older person may insist, "You just don't understand. She's been through so much in her life. She deserves a break."

Once the elder has given a substantial amount to the exploiter, the relationship tends to solidify into three intractable beliefs: (1) that the exploiter is a true friend, (2) that other people misunderstand and wrongly treat this person, and (3) that the person would not be able to make it without this vital help. Efforts to dislodge these beliefs tend to be met with ardent denials. To admit that this "friend" has had motives other than affection would be equivalent to admitting that one has been a fool. Such an admission becomes all the more difficult the more money and caring one has squandered.

Interventions in these situations tend to require a great deal of delicacy, especially at the later stages. Unless the exploiter makes a mistake and does something to puncture the older person's trust, negative statements about the relationship by family members and professionals may only drive the older person deeper into the exploiter's grasp. A better approach is to speak sympathetically about the "friend" and to learn which manipulations are being employed and whether any inconsistencies can be revealed. It may be possible thereby to offer observations that awaken the older person's doubts or at least spur further scrutiny: "Gee, she seems to come around quite a bit at the beginning of the month, just

when you get your check, and then you don't see much of her."

Tragically, ending the exploitation often requires shattering the older person's illusion of being cared about and being important in someone else's life. In these situations, family members and professionals may find that forcing the collapse of the illusion is not worth the pain and humiliation the older person experiences. Instead, they may resign themselves to the continuation of the "friendship," concluding that exploited people have the right to perceive such relationships in the way that pleases them. Unless the original feelings of loneliness and uselessness can be addressed through another means, it may be more humane to permit such relationships to run their course than to intervene.

Untreated Mental Illness

When self-neglect results from untreated mental illness, the person's self-destructive behaviors cannot be considered voluntary and therefore warrant different responses than those described above. Community mental health centers in some areas have outreach programs in which home visits can be made by mental health teams. Getting the person on the proper med-

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ication may spur self-care, along with ongoing case management in which the person is assisted with managing the activities of daily living. In the absence of home-based mental health services, such individuals tend to fall between the cracks. Adult services workers cannot assist them because they lack access to the necessary medications. Mental health workers cannot assist them because they are bound to the office. Occasionally, an adult services worker or volunteer who is able to make home visits on a regular basis may be able to win the person's trust enough to serve as a bridge to mental health services. Once the relationship is solid, the older person may be willing to go to the mental health center for treatment if accompanied by their advocate.

Caregivers Who Neglect Their Own Needs

Overexhaustion by family members taking care of aging relatives is another major form of self-neglect, particularly when an older person gives care to an ill spouse or partner. Some refuse to accept help when professionals offer to locate supportive services for them in the community. Many have no idea what they would do if they had time off from caregiving, having long ago given up on having a life of their own. Some allow the person in their care to abuse them, enduring verbal tirades or excessive demands because they cannot conceive of alternatives. Over time, many let their own needs go to such an extent that the care they provide begins to suffer or they become seriously ill themselves.

Some caregivers decline offers of help at the same time that they complain about their extreme fatigue. When others try to give them a break, they find excuses to go on doing everything themselves. Women are especially vulnerable to falling into this trap, often believing that they should be able to "do it all" as proof of their being a good wife or daughter. Accepting help is experienced as an admission of weakness or a failure of devotion.

Others believe that no one else can do the work as well as they can and that their relative will suffer under someone else's care. They think that a stranger in the house will only get in the way. For example, a 70-year-old daughter may have difficulty accepting a hired housecleaner, despite the fact that she can barely keep up with her 92-year-old mother's care needs. She may also reject her younger sister's offers of help, recalling childhood lapses in her sister's reliability and believing that inferior care would result from a joint effort. She may then feel embittered that their mother's care is falling entirely on her shoulders, going so far as to complain to the very sister whose assistance she rejected.

Strong statements from professionals are sometimes effective in challenging caregivers to adopt a more flexible approach and stop neglecting themselves: "To take care of yourself is to take care of the person you are helping," or "A rested caregiver is a good caregiver; an exhausted caregiver isn't good for anyone." To jolt a tired caregiver into tending to her own needs, it may be necessary to arouse a basic fear by asking, "What do you think will happen to your mother if you keep going like this and get sick?" The caregiver may realize both that she is endangering her relative by neglecting herself and that the care she renders may actually improve if she gets some rest.

Once a caregiver perceives the benefits for herself and her relative, she may be willing to hire a substitute helper on a trial basis. Professionals should urge the caregiver to notice how much more patience she has after she spends time away. She may see that minor flaws in the hired person's work are well worth the improvements in her mood and the quality of the care she is able to provide. She may then become willing to give other relatives a chance, even though they will initially be unfamiliar with the care routines and may not carry out their duties according to her expectations. Accepting that they have to let go of complete control over the situation is often the basis through which caregivers learn how to take care of themselves.

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Self-neglect raises a host of dilemmas. Trying to protect someone may conflict with that person's freedom of choice, yet backing off from protective efforts may leave that person in a risky situation. Offering options, giving information about the likely consequences of various decisions, and trying to convince someone to follow a safe and healthy course of action may be the only responses which respect someone's right to manage their own life. At times it is possible to motivate better self-care by building a relationship with the person, but this requires a large investment of time and caring. ❑

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