

# “Self-Neglect” Cases

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# Mr. And Mrs. Tomas

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- The Tomas's had been married for 40 years, living in the same neighborhood for all but 5 of those years. As the years passed the toll of hard work and relative poverty had started to show in numerous health problems. For Mr. Tomas it was heart disease and cancer and for Mrs. Tomas it was diabetes and now Alzheimer's disease. Because the family thought the changes were all a part of growing old, no one had suggested that she see a doctor about her symptoms. Now she was hardly able to do anything for herself. Mr. Tomas insisted that he could take care of her, that he needed no help, that she was his wife and it was his responsibility to do whatever was necessary to keep her safe and comfortable.



## Mr. And Mrs. Tomas [2]

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- As her sleep patterns changed, he was up for much of the night; he had to take her to the bathroom many times during the day to prevent (or try to) episodes of incontinence. The Tomas's has relatives nearby but he wouldn't let them do anything. He didn't want them to see his wife in the condition she was in--disheveled even though he tried hard to keep her clean-- and unable to do anything for herself. One day a neighbor saw Mr. Tomas on the front steps and was alarmed at what had seemed to happen to him. His clothing hung loosely on his body and his face was ashen. She went up to him but he refused to talk to her.



## Mr. and Mrs. Tomas [3]

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- She decided to call the only number she knew--the local community care agency. A case worker went out to talk to Mr. Tomas. He refused to open the door--said that he was taking good care of his wife. Margie, the case worker explained that it was him she was concerned about. She asked him about his health and when he had last seen the doctor. She told him the services that might be able to help him with his meals and with getting some chores done. He snapped at her and insisted that he was fine and so was his wife. Margie returned several times and could make no headway.



## Mr. and Mrs. Tomas [4]

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- She finally called APS. Joan, from APS, called on Mr. Tomas and fared no better than Margie. He continued to insist that nothing was wrong and that he had everything under control so would they just “mind their own business.” To Joan, he looked terrible and seemed quite frail.



# Mrs. Robinson

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- Everyone loves Mrs. Robinson. She was a childless widow and had been a kindergarten teacher for many years and was known to nearly everyone in the close knit community. Lately, however, she had started to behave strangely. She would leave her house and start wandering around the neighborhood; she'd usually wind up in the playground of the school where she had taught for so many years. She would try to talk to all children but they would run away because she looked strange and spoke in ways they could not understand. The beat policeman called Adult Protective Services (APS).



## Mrs. Robinson [2]

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- When Melissa went to see Mrs. Robinson, her former teacher), she was startled at how Mrs. Robinson looked and at the condition of the house. Litter was everywhere; newspapers piled high; bills stacked on the table; an odor that permeated everything. But Mrs. Robinson was gracious as always. She welcomed Melissa and offered her tea and cookies although she never tried to prepare them.



## Mrs. Robinson [3]

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- The situation was very troubling for Melissa because she was so fond of her former teacher. But she was concerned about her living alone especially in a neighborhood that had so much traffic. What if she started walking in the middle of the street. She began to talk about safety but Mrs. Robinson quickly stopped her: “I’m all right, dear; I’ve lived here almost all my life. Please don’t worry about me. I really want to stay here and if something happens to me, that’s okay.”



## Mrs. Robinson [4]

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- Melissa was startled by this rational statement and thought that maybe others were exaggerating Mrs. Robinson's condition even as she wondered about the somewhat odd behavior regarding the tea. She also, of course, worried about the condition of the house and the hazards for a woman as frail looking as her former teacher. She left but still wondered about what to do.



# Rosie

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- Rosie is very old--nearly 92. She's tiny and spry. She walks to the grocery with her shopping cart every morning and greets anyone she meets on the street. Her children live far away but they call often and visit when they can. At a recent visit to the doctor, the nurse noticed that Rosie's dress had food stains on it and that her hair was uncombed. When she asked Rosie if she needed any help with the laundry or with her hair, Rosie admitted that she was having a harder time doing things that once were easy for her.



## Rosie [2]

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- The nurse contacted a local case management agency and, Randy, a case worker went out to see Rosie. After an assessment, it seemed clear that Rosie needed some assistance with bathing, dressing, and food preparation but now Rosie was adamant that she didn't want any strangers coming into her house.



## Rosie [2]

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- Randy tried everything that he could think of to persuade her that a homemaker could make
- her life so much easier. Rosie was equally insistent that she wanted no help. A few months went by and again, at the the doctor's office, the nurse really began to worry. Rosie looked tired and wore mismatched socks and shoes. Her hair was lanky and dirty looking and her nails were scraggly. When the nurse gently probed, Rosie said, "I am 92 and I can look anyway I want to look. I'm tired of trying to fix myself up."



## Rosie [3]

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- When the nurse weighed Rosie, she had lost 8 pounds since her last visit. When questioned, Rosie insisted that she had been eating but that she wasn't very hungry. Again she called attention to her age and said that she didn't have to eat is she didn't want to. The nurse was familiar with all the stories about vulnerable old men and women whom the papers and then a judge called "abandoned" by the system. She decided to call APS.



## Rosie [4]

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- When the APS worker went to Rosie's house, he was shocked by the total chaos he found there. Empty medicine bottles, dirty clothing on every chair, old newspapers. But worst of all, he saw a few cockroaches on the floor and some of the furniture. Rosie remained cheerful and insisted that she didn't need any help. She had reasonable answers to his questions and seemed not to be bothered by the seeming chaos around her.



# I Am Ready to Die

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- James Howard was a stern old man, now 88 and crippled by Parkinson's disease and further slowed down by chronic back pain. He had very little money but managed to get by with a little help from his daughter and a neighbor. One of them prepared his breakfast on most mornings and sometimes came by later in the day or else left food for him for the rest of the day but he seemed to resent their help more and more. He got increasingly snappy with them. They worried and talked about it but he refused to see anyone. But lately he left his food and refused to eat it or he would take a bite and then shove it aside.



# I Am Ready to Die [2]

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- His daughter begged him to eat and then he'd eat a few more spoonfuls. She started to stay with him to make sure that he ate but that made him angry. One day he told her that he was neither interested in food nor in living any longer. He said he wasn't depressed but his medical problems made it impossible for him to do anything that mattered to him. He'd lived a good life and now it was time to go. He didn't want to eat any more. His daughter called his doctor but Mr. Howard refused to talk to him. His doctor, very worried, called APS and said his client was going to starve to death if nothing was done.



## I Am Ready to Die [3]

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- He wanted someone to do something. Ruth, who had done abuse and neglect investigations for many years, went to see him. He was polite but also irritated and told her in no uncertain terms that his life was his own, that it was none of the state's business if he ate or not and he didn't care what the newspaper articles or the Governor would say if one day he was found in his bed dead.



# Johnny Atkins

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- Johnny Atkins lives alone in a small trailer—the place he has called home for 10 years. He’s been diagnosed with Alzheimer’s disease but so far has managed on his own. His next door neighbor has been bringing him food and paying his bills. He has little use for doctors and doesn’t get out very much. One day, the APS unit receives a call from the postman. He saw Johnny sitting by the window but when he called out to him, Johnny didn’t respond. He also noticed growing piles of litter around the house and no one seemed to be home next door since the mail had been piling up. The postman was alarmed and so make the call. Within a day or so, you also get some calls from neighbors who worry about the accumulating garbage.

# Clutter or ???

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- Sadie Roberts, at 86, lived in a studio in a low income housing development for older people. She'd lived there for 3 years. Her daughter and son visited only occasionally although they lived in had lived in this part of Texas for most of her life so she had many acquaintances even though most of her friends and her husband had died some time ago. She was friendly but seemed to have no really friends.





## Clutter, [2]

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- Her neighbors started to complain to management that the odor coming from Sadie's apartment was really bad. They also had noticed that sometimes she appeared distracted and disheveled in appearance, an oddity since she had always seemed to pride herself on her appearance. The manager finally called APS because the stench became so bad that neighbors on the floor below started to complain. The case worker went to Sadie's apartment; Sadie was immediately suspicious but finally let her in. Tracy, the case worker saw total disarray around her—a dog that seemed hungry and lethargic, trash piled high, no food in the refrigerator.



## Clutter [3]

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- Sadie answered Tracy's questions but certainly did not see anything wrong with her living situation. She refused all offers of assistance, insisting that she had lived this way all of her life and had no intention of doing anything differently at this point.



# Giving Sadie Real Choices

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- Are there alternatives that reflect a healthier version of how she wants to live?
- ✓ What might those alternatives be?
- ✓ Are there choices that connect her to the familiar?
- Can the state offer her comfort and security without taking away her psych-social safety?
- Can she “test” out alternative living environments?



# Maxine and Trudy

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- A hospice nurse, Rae, made a hotline call after a visit to a new patient. When she arrived at Maxine's house for the first visit she was greeted by Trudy. Trudy identified herself as Maxine's caregiver. Maxine was in her late 70s and was dying; she had a brain tumor that has effectively destroyed her ability to move and to communicate. Trudy told Rae that she stayed with Maxine 24 hours a day, that she loved her like a mother and that the only other regular visitor that Maxine had was her younger brother Joe. Trudy had been Maxine's caregiver for several months but it was only in the past month or so that she started staying overnight. Rae wondered about Trudy's devotion but then was startled when Trudy said, "sometimes I get into bed with her." Rae didn't ask any more questions but came immediately to her employer and insisted that a call to APS be made. She was upset that Maxine could not make her wishes known and that Trudy might be sexually exploiting her.



## Familiar Ethical Issues (Some indirectly related to self-neglect)

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- ❑ Safety vs. risk (e.g, home or institution? assisted living?)
- ❑ Promise keeping (e.g., never place in a NH)
- ❑ Truth telling (e.g., diagnosis)
- ❑ Advance directives (e.g., to honor or not?)
- ❑ Confidentiality (e.g., impaired professionals; impaired colleagues)



# Other Ethical Concerns Relevant for APS

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- ❑ Meaning and Identity
- ❑ Dignity
- ❑ Respect
- ❑ Caregivers



# The Basic Ethical Problems in Cases Involving Neglect (and Abuse)

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- Dual and contradictory mandates: protect the client from harm; honor his or her choices
  - Fundamental problem in ethics in general and most wrenching in self-neglect situations
  - Freedom is always limited because:
    - resources to do everything we think needs to be done are unavailable
    - choices of what we can make available to the client and the family are also limited
    - We are vulnerable to the influence of others
- Competency or decisional capacity is rarely all or nothing (sometimes it depends on what is being decided)
- It is rarely about the person alone



## A Word about the “Social Compact”

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- Reciprocal ties among individuals, families, communities, government
- Sometimes we must act for the good of others even if it conflicts with our own good
- And some people are especially vulnerable to “unnecessary suffering”
- Making the social compact critical



# And Therein Lies the Problem

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- How to decide what risk is too much risk?
- Must evaluate both capacity to decide and level of risk—the greater the harms that can result the greater degree of decisional capacity necessary. Remember that it rarely all or nothing
- But that is not all-----



# Importance of Context

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- No cookie-cutter answers
- Enter situation that is already laden with the past and the problematic present
  - ✓ Family relationships are usually decades old and so are the problems
  - ✓ Significant incidence of cognitive impairments with co-existing medical conditions
  - ✓ Effects of isolation, depression, feelings of abandonment and hopelessness
  - ✓ How did the person live before



# Regnant Value of Autonomy

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- If it doesn't do harm, we ought to be allowed to do it
- Every benefit of the doubt is given to autonomy
- Scale is tipped heavily toward autonomy enacted as self-determination



# A Counterweight

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- ❑ Should we be allowed to bring grave harm upon ourselves?
- ❑ Are there any social values that ought to count?
- ❑ What does it say about our society if, in the name of self-determination, elders live in squalid and dangerous conditions?
- ❑ What does it suggest about social obligations to give people real choices so that they can act in a more fully autonomous manner?



# A Middle Ground

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- “. . . Need to start over and quit seeing it as a safety-versus-freedom issue. It’s more an issue of are we going to try to heal and restore people, or are we going to maintain that it’s up to individuals to get what help they need, and (let them) deal with whatever has happened to them in their lifetimes on their own” (Loree Cook-Daniels, Amer. Soc. Of Adult Abuse Professionals and Survivors).