

Earl, 59 year old man with autism and physical impairments What people like and admire

Helpful Polite A good laugh Competitive Inquisitive

What is important to me

Seeing my mom and dad at least once a week. I love motor racing, especially team MaClaren and watching the Grand Prix, it doesn't matter if I've already seen it! My hero's are Jensen Button and Lewis Hamilton. Playing on my play station most days with the volunteers who come in to compete with me. Seeing my uncle every Sunday going out together, we love going the cinema or if the weather is good doing my uncles garden. To go out everyday, not to anywhere in particular as long as I am getting out and spending time with people. I'm always the first person to say yes to any suggested outings. Having friendships is important to me, in particular with my friend Dave and Lois who supports me. Going to as many airshows, as I can get to. I love all airplanes and am fascinated by the RAF. I must wear my RAF hat and bomber jacket whenever I go out. Leeds united are my football team and I love to go to live matches and taking part in the lively banter. If I don't get to a match I watch the games on the TV with mates. I really enjoy getting involved in the whole atmosphere of the game. Watching films, especially ones about airplanes. Top Gun is my favorite. Having fish and chips every Friday from my local restaurant or when I am having a day out.

How best to support me:

Know that I always get up early and enjoy being the first person up and about, I'm a morning person and my staff need to be cheerful and chatty with me. Knowing everything that is going on matters to me, I ask lots of questions about anything that interests me, if you don't have the answer immediately let me know when you will get back to me. I must have a newspaper delivered daily, but especially like to read the films section on a Friday. Know that I will want to be the first person to have a read of the paper. My room must be exactly how I want it. A place for everything and everything in its place. When you support me with household tasks, know that I will do as much as possible for myself. I will ask you if I need more support. I use my foot supports everyday to prevent pressure areas before starting to use my wheelchair. Know that I will always put these on myself, check that they are adjusted correctly.

Case Study

Rita, 49, lives in her own home with care staff who have known her for more than 15 years. She is nonverbal, using signs and grunts to communicate her needs. Diagnosed with autism, her developmental age is 1 1/2.

Rita's primary caregiver reports that she has been much more irritable than usual, sometimes hitting and spitting at staff. Her sleep routine has changed over the last three months. She has been getting little sleep, with no more than four hours of uninterrupted sleep per night.

She is visiting the physician's office/clinic for the first time and is scheduled for a new patient exam. Rita's previous physician encounters addressed only specific urgent physical matters.

Preparation

Weeks prior to Rita's appointment, it was necessary to assess the pertinent information related to her visit, as follows:

- If Rita can't make treatment decisions independently, who is responsible for doing so?
- Can Rita's caregiver provide any background information about previous physician visits, hospitalizations, dental care, and/or psychological testing? Can the caregiver provide consent to obtain information from Rita's other health care providers?

What other questions or considerations should be taken in order to correctly prepare Rita and/or her staff for this visit?

SCENARIOS

Ethical Practice in Meeting the Needs of Aging Individuals with Disabilities

- 1. Jim is a 60 year old man with autism, who is wearing his favorite T-shirts daily to his work sites, to community bowling activities, on walks around the neighborhood. Most of them are Tweety bird t shirts, although he also likes Cookie Monster and Elmo. At times, people in the community do double takes, and occasionally he receives unkind remarks. Is this an issue in need of review with the individual served, with the team? Should attempts be made to have him wear more age-typical clothing? Should any discussion take place about contexts in which such items are less appropriate?
- 2. A 62 year old woman, Dolores, who has autism, has begun wandering unexpectedly. The behavior analyst was called, and she quickly indicated that she should lose points on her weekly token system for wandering. The plan is implemented, to no effect. What is missing from this scenario? What should the behavior analyst be thinking and doing?
- 3. Lately the team has struggled with choice in the context of their elderly clients. For instance, Ray, a 70 year old man wants to smoke a cigarette after program, before dinner, and before bed. He has some coughing and in not in the best of health, and smoking is not recommended by his physician. However, he wants to have three cigarettes a day, and is insisting it is his right. Johanna, a 63 year old female client, has developed high blood pressure and high cholesterol. She is on medicine for both and they are under good control. She is being stopped by staff members when she orders fried chicken or cheesecake at restaurants, and it is causing behavioral escalations.
 - a. How should these situations be viewed in the context of choice?
 - b. Are staff entitled to interfere in these ways?
- 4. Bill is a 59 year old man with autism who has been having different sleep habits over the past several months. One change is that he wakes a few times a night. Luckily, he does go back to sleep and the disrupted sleep does not seem to interfere with wakefulness or energy the next day. Recently, upon waking during the night, he showers. He is independent in the shower and non disruptive. He does not have a roommate. Staff have been refusing to let Bill shower, telling him that showers are before bed or upon waking only. Is this a violation of his right to choose basic elements of his day? How should this be managed?
- 5. John is a 72 year old with autism who no longer goes to employment. He now does not want to go to day program. He wants to doze, watch TV, and take rides. Staff are confused about how to manage his programs and skill acquisition targets. They are cajoling him to go to program, and are then making him do programs. Is this appropriate? What are other solutions?

ENGAGEMENT PLAN (GAME PLANI)

What are the activities this person enjoys individually? (LIST THINGS THEY CAN BE APPROPRIATE AND INDEPENDENT WITH!
1. 2. 3. 4. 5.
What are some things you could do WITH this person? LIST THINGS THEY ENJOY BUT CAN NOT DO ALONE AND WOULD LIKE TO DO WITH STAFF MEMBERS 1. 2. 3. 4. 5.
MAKE A SCHEDULE FOR THE DAY, LISTING EACH HALF HOUR AND IDEAS FOR WHAT COULD BE PROVIDED (MIX individual and interactive)
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2.
3.
4.
5 *:)
6.
7.

8.
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12.
13.
14.
15.
16.
Come up with three ideas for waiting in breaks that could engage the individuals better
1.
2.
3.