FORWARD

This paper is part of a series presented by HSS Inc. and the TEAM® (Techniques for Effective Aggression Management) educational program. These resources are designed to share research and analysis, guidelines, tips and techniques for action in the fields of education and training. Our goal is to provide credible sources of information and evidence-based solutions so that individuals and organizations have the tools and resources they need to effectively manage aggression in the healthcare setting.

We are committed to developing and delivering the highest quality educational programs and materials for healthcare professionals. This paper is a resource for those facing the growing challenge of violence in healthcare, which continues to increase at an alarming rate in the United States – a noticeable 37% spike in the past three years alone! Effective de-escalation skills are as much an ‘art’ as ‘science’ when it comes to managing someone who suffers from dementia.

The TEAM® (Techniques for Effective Aggression Management) and ED-Safe™ programs are healthcare-specific violence intervention trainings that take a proactive, multi-tiered approach in managing the environment as well as de-escalating the aggressive and violent individual. TEAM® and ED-Safe™’s proven prevention and mitigation strategies help create a culture of safety in all sizes and trauma levels of healthcare organizations.

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INTRODUCTION
Advanced dementia may represent the potential for violence against caregivers, and as our nation grows older, the likelihood of coming into contact with someone who has dementia increases. However, dementia, in and of itself, is not simply part of the aging process. Dementia is a developmental disorder of brain function. It is progressive and incurable. It therefore creates challenging and unexpected changes in a person's mood, thoughts, and behavior that caregivers and professional staff may find difficult to manage and somewhat disconcerting.

Communicating with someone who suffers from dementia can feel like a dance. The caregiver (whether family or professional) is in a continuous loop of recognizing and responding to behavior. For responses to be effective, they must meet the person's immediate need, for which there may be a combination of emotional, physical and intellectual considerations. What works today may not work tomorrow, and effective actions may feel counter-intuitive. This whitepaper provides guidance on identifying common symptoms of dementia that staff may encounter and offers de-escalation techniques recommended by allied health professionals and community resources.

THE CHALLENGE
Daily, healthcare and facility staff communicate with people who have dementia. When presented with bizarre behavior, or a person who appears unwilling to cooperate with direction, it is normal to try to place boundaries on that person's actions. Expectations of compliance and self-management are part of our social fabric.

Cognitive impairment caused by dementia, and the resulting behavior, is not an act of willful disobedience. Dementia can be caused by one or more of at least 26 identified sources ranging from the on-set of Alzheimer's Disease, to drug interaction, to a closed head injury and more.

This white paper focuses on dementia as a progressive communication and information processing disorder. As the illness progresses, people lose their problem recognition skills and the ability to match a problem with an appropriate response. Examples of this type of disconnect include elderly people who wander away from home, and confused drivers who don’t know where they are, or how they got there. As the disease progresses, friends and family no longer look familiar, and the person with dementia may become agitated or accusatory toward those they love and trust most.

Other illnesses and conditions have these very same symptoms; however, with dementia, while there may be instances of clarity and what may appear as remission, the illness in fact will continue to take its toll on the individual’s cognitive function and memory. This cycle alone is confounding to the person and those around him/her. Confusion, loss of the sense of being in control of one's own self and often difficult behavior become part of daily life.

An elementary understanding of the disease process helps to comprehend the physiological changes a person experiences at the onset of dementia. The brain has four lobes, with each lobe controlling different functions. The cerebral cortex surrounds the brain, and, when dementia attacks the cortex, the connections between brain cells die leaving spaces that force the brain to shrink over time. Three of the four lobes are directly affected by dementia: Frontal Lobe (executive functions including intelligence, judgment, behavioral control); Parietal Lobe (language center); and the Temporal Lobe (memory). The fourth, the Occipital Lobe, controls vision; and research has not shown it to be primarily impacted by dementia.

The word dementia is used to describe several types of disorders that cause impaired brain functioning. The most common form of dementia is related to Alzheimer's Disease (AD). The Seven specific phases of AD have been identified in the research literature, and three general phases of dementia, listed below, have become a standard description of the process.
WHILE ALZHEIMER’S IS THE MOST COMMONLY KNOWN DISEASE WHERE DEMENTIA IS A PRIMARY IDENTIFIER, DEMENTIA CAN BE UNDERSTOOD AS A THREE PHASE PROCESS RATHER THAN A DISEASE ITSELF.

PHASE 1
Mild impairment that can be easily shrugged off as normal aging. Forgetfulness is a key indicator and in this early stage, tools like notes, calendars and other reminders work well to maintain functioning. The person is aware they are not thinking and remembering as clearly as they have in the past but these lapses are often attributed to stress, over-scheduled calendars, etc.

PHASE 2
Moderate impairment sets in identified by significantly impacted short-term memory. The person tends to ask repetitive questions as though for the first time and appears anxious, sometimes paranoid, about upcoming events. Anxiety and depression may be diagnosed in this stage as the person becomes more aware of losing control of their life. Self-care and self-management are clearly problematic; hygiene is also affected. Socially, the person may withdraw as they are aware they cannot communicate as well as in the past, which creates the dual sense of frustration and loss. Intellectual interests, active participation in events and individual hobbies that were previously important are abandoned as this phase progresses.

PHASE 3
A high degree of impairment is now present and the person’s condition cannot be covered up. Assistance with daily living is necessary as independence is not an option. The areas of the brain are significantly affected and the person may become non-verbal. Home-based care at minimum is necessary, and, since many people experience loss of motor function and behavioral management, care in a specialized facility may be indicated.

Communication with a person who has dementia can be rewarding and frustrating within the same five minute time span. There are common themes to creating the best outcome for responding to someone who is upset and escalating their troubling behavior. The next section will explore recommended strategies to help ease the situation and guide the upset person in finding relief from the stimulus, if not resolution to the issue.

COMMUNICATION STRATEGIES
Behavior is purposeful for those who have dementia and for those who do not. A difference, however, is that for those who have dementia, the person’s reaction may have no logical relationship to the trigger (stimulus). For people in the mid- to later stages of the disease, agitation may turn to aggression and even physical violence. The use of tone, volume, simple sentences, rapport-building, body language, distractions, and creative problem solving can redirect the person and manage escalating behavior positively and proactively.

Specific Techniques
In most cases, a combination of the techniques described below will be most effective in managing the escalating behavior of a person with dementia.

- Setting the atmosphere, when possible, is a good start to managing troubling behavior; that is, a waiting room or other area with a calmer, less stimulating environment is preferable to the hub-bub of an ED or public area.

Voice tone, modulation, and speed are critical elements. Use a respectful tone, normal volume and a slow, even speed to ask questions and provide directions. Ask one question at a time and patiently await the answer. Provide directions similarly, in logical steps.

Use eye contact that fits the person’s social and cultural identity. Maintain an open body position that shows interest in the person. In some cases, a gentle touch on the arm is useful to maintain or regain contact. Touch can be a calming and connecting experience; be certain that agency/facility protocols are maintained and that the contact is welcome.

Get the person’s attention by using his or her name. Introduce yourself more than once and explain your role if they do not recognize you or cannot remember this information throughout the course of the intervention.

Patience is key. The person with dementia is not purposely trying to be difficult. Often they are extremely frustrated by
their own lack of control, as well as anxious and embarrassed. Some people will escalate with anger and accusations. Do not get caught up in this “argument,” rather, listen to the person, and reassure him/her that the problem can be solved. Fear is a prevailing feeling for those with dementia. Providing a sense of safety can be the number one response they need.

When responding, use sentences that are simple in structure and language. Use names of people and places that may trigger anchored memory recognition for the person.

Helping with sentence completion/word finding is useful, as long as the listener has given a fair amount of time for the person to state his/her thoughts or feelings. Gaps in language processing are quite common, and words seem to have simply disappeared for some people, or the word is no longer recognized. Patiently assist the person in describing what it is they want or need by getting clarification on the item, task, or person for which they are searching. As one caregiver guide states, “Always strive to listen for the meaning and feelings that underlie the words.”

Break down activities into specific steps. This is imperative to individuals with dementia because when they are in crisis-mode, they are not able to process complex actions; therefore a step-by-step approach is most effective. “Mr. Jones, I see that you are upset, please go to the green chair and sit down.” By giving directions in single tasks, the staff member can better assess what the person is capable of doing and comprehending.

Distraction from the upsetting stimulus and redirection are strongly recommended techniques. A redirection may be as simple as moving a few steps, going for a walk down the hallway, or finding a quieter place where the person can describe what is upsetting them. These simple redirects may help guide the individual to let go of the trigger altogether. Options such as pointing out an object that may be of interest or changing the subject may also work in many cases. The objective is to change the person’s focus away from the upsetting stimulus and toward something else he/she might find engaging.

Build rapport with the person. That is, genuinely engage them in a conversation. This not only is a potential path to assessment of the level of understanding and functioning, but also may have a calming effect. Engagement is the act of respectful question and answer exchange, reflection of feeling, and the offering of information. Directives provided in an engaging way are more likely to result in positive behavior change by the patient than communicating in a less engaging/forceful manner. People with dementia are struggling enough with control and recognition, therefore providing a team-oriented environment may foster more engagement and cooperation.

Attempts at “truth-proving” will be fruitless. Avoid trying to convince someone they are wrong or that their confused state has led them astray. Simply find out what the person wants/needs and problem-solve from that angle as a team.

Accommodating the person’s behavior may be the best response, at least in the short term. If the person insists on something that does not put him/herself or others in danger, try accommodating the request. The patient may lose interest immediately following the accommodation. If there are options from which to choose, try limiting the choices to two: “Which do you want, the blue shirt or the green shirt?”

Remember, your sense of humor and perspective are very important tools for managing your own response to someone in crisis. The person’s crisis is not about you. Try to meet the person with dementia “where they are” and recognize the limits of what is possible for that person. Trying to see the world from his/her perspective might enable you to respond in a more appropriate manner.

Safety is the top priority for all involved. Some people with dementia escalate to violence. If a person is physically out of control, additional staff may be needed to prevent further harm to him/herself and to others.

Some individuals have such an advanced stage of dementia that they non-verbally express physical pain by acting out aggressively and/or violently. They have no other means to declare the pain they are feeling other than through physical means. Caregivers should evaluate such patients for the presence of injury or other pain-causing conditions.

FEAR IS A PREVAILING FEELING FOR THOSE WITH DEMENTIA. PROVIDING A SENSE OF SAFETY CAN BE THE NUMBER ONE RESPONSE THEY NEED.
Hallucinations occur in some cases for those who have dementia. The two most typical types are auditory and visual. As with any person who is actively hallucinating, offering safety is the best approach. People who are hallucinating may be aware it is not real on some level, but cannot easily pull out of the experience; others cannot distinguish the hallucination from reality. Attempts at convincing someone the hallucination is not real are not useful; rather, a better course is redirecting the person’s attention to some area that feels safe to them and where there is low stimuli.

Triggers of resistive behavior may also include bathing time, a change in dining or dressing habits, doctor appointments, and any activity that places the person in an uncomfortable role. While these are everyday tasks, the loss of control and invasion of privacy may trigger reluctance to cooperate or even prompt highly agitated responses. The literature consistently recommends these approaches: breaking down the task into steps; using a calm, reassuring tone of voice and language; and, using redirection to another activity and trying the desired task again after the person has regained a sense of self-efficacy.

SUMMARY
Recognizing the signs of dementia and impaired communication is key to creating an effective response. Those who have dementia often feel very out of control and want desperately to maintain some sense of dignity. This struggle to be, or look, competent may come across as obstinacy in a healthcare setting. In extreme situations, the person’s agitated state can present the threat of violence to healthcare professionals.

From a social norms perspective, there is an expectation that people conduct themselves in a proscribed manner that includes acceptance and willingness to respond to others. However, dementia steals cognitive processing and rationality, thereby placing individuals and healthcare providers in a situation where proper training and understanding is critical to a successful outcome. Finding the pathway to cooperation and resolution for all involved requires an understanding that the person is not willfully responding to the staff member, but that they need help in managing his or her own behavior.

The approaches described in this white paper are from several resources and include suggestions on how to weave multiple techniques into a successful response. A comfort level with the techniques will develop over time for staff members, as they practice and gain experience applying them. Engaging with a person with dementia, meeting him/her “where he/she is” and de-escalating what is likely a frightening experience for him/her can be done deftly and will help create a sense of safety for the person as well as reinforce the staff member’s competency and mastery of these techniques and can result in a more positive clinical experience for the patient.

REFERENCES AND RESOURCES
Communicating Effectively with a Person Who Has Alzheimer’s, (2002), Mayo Clinic Staff, www.mayoclinic.com
Family Caregiver Alliance (free, on-line fact sheets)
785 Market Street, Suite 750
San Francisco, CA 94103
(800) 445-8806
www.caregiver.org