

# VOICES OF AMI TRAINING

## Restraint and Excess Disability – both examples of elder abuse?

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Alzheimer's Disease International reports that in 2020 there were estimated to be over 55 million people living with dementia. This number is projected to double every 20 years, reaching 78 million in 2030 and 139 million in 2050. Every 3 seconds someone in the world develops dementia. It is currently the seventh leading cause of death and one of the major causes of disability and dependency among older people. Most people will be affected by dementia in some way at some stage of their life.

We have worked hard over recent years to change stereotypes and the often-negative approach to people living with dementia, but sadly, even today many attitudes remain negative and rob a person living with dementia of their rights for respect, understanding and quality care.

Dementia has often been referred to as the long goodbye. Along with the diagnosis comes a variety of challenges which are closely associated to the devastating effects of memory loss, including disorientation to time, place and person. As time passes, the cognitive decline becomes increasingly apparent with a combination of behavioural concerns that can occur such as wandering, repetitive questioning, and agitation. As the number of people living with dementia continues to rise, it becomes increasingly important to find meaningful, purposeful and enjoyable activities, at the person's own level of ability, which are designed to enhance quality of life. Appropriate evidence-based interventions are needed to avoid abuse and help people with dementia end this last chapter of life with dignity, respect, meaning and a sense of worth.

Montessori methods for dementia focus on supporting both the person living with dementia and the environment in which they live. The techniques are intended to engage people with dementia in life and living, by providing an environment that supports their losses and circumvents their deficits whilst providing meaning and purpose to their day. It is a model that calls out abuse of any kind and provides options whereas once abusive strategies existed.

Montessori methods focus on a form of learning that fits within the framework of rehabilitation and excellent overall dementia care. While activities adapted within the context of rehabilitation are not expected to return the person to his/her pre-morbid state, they can be used to maintain and enhance cognitive, psychosocial and physical function. For some people the use of Montessori activities can enable them to re-learn skills required for activities of daily living.

When a person is diagnosed with dementia, their freedom of choice is in danger of becoming defunct. Decisions are often made on their behalf because it is assumed that they are no longer able to make any decisions. It is often others who decide what a person living with dementia will eat, what they wear, what they do and when they go to bed.

In a Montessori environment a prepared environment provides opportunities for social roles, expression, support, independence, interpersonal connections and social abilities that promote social confidence – an atmosphere of both caring and being cared about. A prepared environment also stimulates the senses, encourages exploration, choice and provides opportunities for self-initiated activities. People cannot be engaged in a meaningful activity and wander, intrude or exhibit other behaviours of unmet need at the same time. People in care communities are left for too many hours with nothing to do.

Dementia is associated with a set of characteristics and features that accompany each stage and type of dementia. The ‘actual’ disability creates many challenges for both the person with dementia and their care partners. This is accentuated when we take away roles, routines, and activities.

A common form of abuse seen in care communities is that of Excess Disability. When we over care, disability can quickly change to “excess disability” that arises from disuse of remaining abilities. We create Excess Disability when we use a wheelchair to take a person to the dining room because it is quicker than them walking themselves, we create excess disability when we feed people because it is quicker than them feeding themselves or when we pour a drink for a person who is able to pour a drink for themselves or when we dress a person who is quite capable, happy and able to dress themselves.

Often in care communities, things are done in a particular manner to make things easier, faster and better for staff. A subtle form of abuse, often carried out with the best intentions that is often misguided and deliberate.

In addition to the prevalence of Excess Disability, sadly, restraint is still used in many countries around the world as a strategy to manage people living with dementia. I once asked why families accept such practices and the answer I received was that families are often so grateful for care that they do not want to complain. Knowing they are unable to care for the person themselves, they are just grateful for the care provided. Tying people into beds or chairs, over sedating people with medication, removing walking aids or locking people in rooms are all totally unacceptable practices.

We need to advocate for people living with dementia, we need to be their voice, and we need to say no to practices that create excess disability and we need to say no to restraints of any kind. Both these practices are forms of abuse and we need to call them out as such.

We need to hear and see with not only our ears and our eyes, but also with our hearts.

### **ABOUT THE AUTHOR**

Anne Kelly is a registered nurse and an aged care Montessori Consultant. She holds post graduate qualifications in Dementia Management as well as workplace training and assessment. Anne has worked extensively in both residential and community-based dementia care for the past 40 years. She has been an aged care Montessorian for the past 15 years and is considered an Australian and world leader in Montessori Methods for aged care. In June 2021 she joined AMI as Head of Montessori for Dementia, Disability and Ageing.

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