Zero tolerance of restraint

10 points for zero tolerance for the use of restraint in persons with dementia

(what we have learned in the programme "Untie the Elderly and People with *Dementia*" in Spain)

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http://www.alzheimer-europe.org/EN/Ethics/Ethical-issues-in-practice/The-ethical-issues-linked-to-restrictions-of-freedom-of-people-with-dementia/Appendices#fragment-2

TEN POINTS FOR ZERO TOLERANCE

1. As evidence shows, a person with a progressive cognitive impairment will be physically or chemically restrained at some point of their disorder
2. Reasons for using restraint are myths and reality has disproved them.
3. Variability in the use of restraint: why?
4. Consequences of the use of restraint on the health of patients. Mobility is necessary to preserve functional autonomy.
5. Consequences of the use of restraint for professionals and for the caring organisations.
6. The use of restraint for convenience.
7. Resurgence in the use and development of new and subtler forms of restraint.
8. The use of restraint generates ethical and legal conflicts. How much safety can be demanded?
9. Restraint-free facilities.
10. Zero tolerance is an engine of improvement. Everyone wins.

INTRODUCTION

It is the loss of judgement, the inability of people with dementia to govern themselves and *behavioural symptoms*, which lead us to restrain people with dementia. Regarding physical and chemical restraint, the most important factors are behaviour and anosognosia.

Zero tolerance of restraint is an attitude of professionals who care for people with dementia. It is an attitude which is spreading throughout Spain amongst professionals from different fields who do not accept the routine use of restraint.

Zero tolerance is now a common attitude in other medical areas where professionals do not accept the negative consequences of such practices in their work. It is the only approach which gives clear and sustainable results (e.g. zero tolerance of ventilator-associated pneumonia by professionals in critical care units).

As a norm, zero tolerance does not use restraint. Like every norm, it has exceptions, but only for extreme and isolated incidents.

The data which we have regarding the condition of the residents in the restraint-free facilities allows us to affirm that not using restraint is safe, just as safe or even safer than the facilities where restraint is used on a daily basis. This data also reveals that the restraint-free facilities (which have been restraint-free for months or in some cases years) have not had to make an exception for extreme cases.

Knowing the effect of the daily use of restraint, many professionals have begun to refuse to consider restraint as an option and to acquire an attitude of zero tolerance. They face an ethical conflict between the duty of care and the duty to protect and respect the person and promote their *autonomy*, accepting a degree of risk, as an essential part of good care.

This document is intended to facilitate the resolution of the conflict through strong arguments in favour of this attitude of rejection of the use of restraint, based on new knowledge and new experiences that invite us to change the paradigm of care.

BACKGROUND

Untie the Elderly and People with Dementia Programme

The Untie the Elderly Programme was founded in Spain in 2003. It was developed in collaboration with the **Spanish Confederation of Seniors (CEOMA)**.

In the first years, we worked on:

Understanding well the problem with the use of restraint in Spain and identifying the characteristics of this phenomenon.

Investigating the prevalence of the use of restraint in Spain and the related clinical factors.

Investigating the perception of professionals on the use of restraint.

After, we also worked on the creation of a favourable context to untie the elderly by:

Information campaigns

The promotion of specific laws

Training

Scientific activities (two international conferences on restraint in Spain)

And during this time:

We carried out fieldwork in dozens of Spanish facilities to identify the organisational and environmental factors related to the use of restraint and to find the key to avoid them.

We continued providing data on prevalence and related factors. Today we have data from 687 facilities and 29,332 residents.

Over the last three years, we have focused on establishing restraint-free facilities, which serve as examples. We have learnt that working without restraint is possible and safe and that the key to doing so is the Zero Tolerance concept. We now have 28 restraint–free facilities in Spain. The declarations contained in this document refer to the Spanish experience, with data and conclusions obtained from the work of the Programme over the last ten years and from reviewing publications on these issues from different countries.

We have always worked according to the following definitions:

Physical restraint: "Any manual method or physical or mechanical device, material, or equipment attached or adjacent to the resident's body that the individual cannot remove easily which restricts freedom of movement or normal access to one's body."

Chemical restraint: “A medication that is used to control the behaviour or restrict the freedom of movement of the patient and which is not a standard treatment for the medical or psychological condition of the patient”.

TEN POINTS

1. At present we can be sure that a person with a progressive cognitive impairment will be physically or chemically restrained at some point of their disorder.

Cognitive impairment is a predictor of the use of restraint. This has been clearly identified in the literature but admitting that an illness can condemn a person to be restrained at some point of their illness can be like admitting professional failure for many professionals because it shows that they are not capable of understanding this syndrome well or of managing the symptoms in a less aggressive and damaging manner. This is the case for people with dementia especially if they reach more advanced *stages*.
Cognitive impairment is almost always present in people who are restrained, although it is true that resorting to restraint usually happens when cognitive impairment is combined with other conditions/symptoms such as "wandering", serious behavioural disturbances or the risk of falls. Observation and data from the Untie Programme show that all residents restrained in Spanish facilities show some degree of cognitive impairment.
It is very difficult to obtain accurate data about the use of chemical restraint but we have data on psychotropic drug use. These medications have become the *dominant* approach to the management of BPSD (Behavioural and Psychological Symptoms of Dementia).
We carried out a qualitative study on the use of this medication in Spain that showed the following:

- It is not always possible to find the cause, indication or objective of the use (76%).
- It is not possible to evaluate the negative impact on the patient in an objective way e.g. through *ADL* (Activities of Daily Living).
- A high frequency of PRN (when necessary) use (36%). A low frequency of dose adjustment (18%).
- Chronic use (over three months, same medication and dose) (69%).
- Prescribed outside the context of Care Planning (100%).

These characteristics of use are related to the purpose of restraint.

2. The reasons for using restraint are myths and reality has disproved them

The use of restraint continues to be justified today because:

1. By using it, falls could be avoided.
2. Not using restraint is sometimes unsafe for some cases of people with dementia.
3. Avoiding using restraint means an increase in the number of staff in nursing homes.
4. Families demand absolute safety for their loved ones who are incapable of caring for themselves.

People also continue to believe that physical restraint can be avoided if chemical restraint is used, and that antipsychotic medication is always useful to control the behaviour of people with dementia.

We now know that all of the above are false.

TRUTHS

Nowadays, restraining people cannot be seen as a valid means to prevent falls as it always turns into a daily use of restraint, which has worse consequences than a possible fall. The routine use of physical restraint increases the risk of falls, and most of all, it increases the risk that injuries from the falls will be more serious. Older long-term care residents receiving antipsychotic drugs are two to three times more likely to experience a fractured hip than residents not receiving this medication.

We know with certainty that the removal of restraint is safe provided that it is done properly.

We also know that physical restraint cannot be substituted by chemical restraint as the two go hand in hand. Chemical restraint is associated with a high risk of falls with serious injuries, and we know that the risk of falling is the main reason given for using physical restraint daily. Residents express twice as much agitation when they are physically restrained and this problem is linked to the use of chemical restraint.

We know that, in general, the use of antipsychotics is not a good means to control the behaviour of people with dementia, except in a few cases and for short periods of time. In general, "non-pharmacological therapies" are as useful as or more useful than medication in dealing with the "behavioural and psychological symptoms of dementia" (BPSD) and they are definitely safer. The literature on antipsychotic drug use in dementia can be summarised as follows: These drugs are harmful, they are ineffective in treating behaviour, and their use varies significantly from facility to facility according to the culture of the facility, and not the characteristics of the patients.

It is not necessary to increase the number of staff numbers in order to work without the use of restraint. Working with measures of restraint and working without them are two paradigms of care which are different from each other but which have similar workloads, although the work in each case is different. The nursing homes which have converted to restraint-free facilities in Spain did so without an increase in staff numbers.

We have also learned that family members of the patients who are well informed generally consider the removal of restraint as something positive. The facilities can offer reasonable security without using restraint, which makes a higher degree of well-being possible, and also more physical, mental and psycho-social autonomy for the people living there. Well-informed relatives tend to choose quality of life.

One of the conditions of the Spanish Untie Programme to help eliminate the use of restraint in facilities is to inform relatives of the new policy of the facility. Informative meetings are held, leaflets are published and references to the internal regulations of the facility need to be included in the contracts that are signed. In cases where restraint had been used with prior consent, the legal representative is asked to sign a document authorising the removal of the measures of restraint. Only three cases from a total of 28 restraint-free facilities, with 1566 residents were reported to the Programme of families which were against the removal of the restraint. These families maintained this position for three months before finally accepting the removal of the restraint.

3.Variability in the use of restraint: why?

The variability in the use of restraint, observed in different prevalence studies, is not explained by the condition of the residents in the facility. In the database of the Spanish Untie Programme, we have facilities with 0% prevalence of physical restraint use, and facilities with a prevalence of 67% (in extreme cases), with a similar case-mix of residents.It is easy to deduce that the determining principle of the differences in use observed is in the cultures of the organisation and hence the different attitudes in these organisations. We believe that there are contextual factors which influence (in a determining way) the attitude of the organisation and its professionals towards this practice. We also believe that the most important of these factors are the ones that generate a perception of legal insecurity in the workers and their bosses, and a social tolerance which is common for certain types of restraint and for certain cases. Differences in the use of restraint can be observed also between countries, which suggests that there is also a social factor involved.

4.Consequences of the use of restraint on the health of the patients. Mobility is necessary to preserve functional autonomy.

There are many references which show the effects of restraint on people's health. The majority of them are linked to the consequences of inducing immobility on the person, making it impossible for the person to move, or due to lack of strength/vigour and physical exhaustion (adynamia) in the case of chemical restraint. Immobility is considered a syndrome and the effects on the person with dementia are well documented.

As well as immobility, physical restraint also causes other complications in the patient, some related to rejection and struggling and others related to the psychological effect of being restrained, with serious behavioural problems and, most of all, agitation. Medication used for restraint has serious negative secondary effects on people with dementia, especially if administered daily in combination with other medication. In behavioural terms, they can triple verbal aggressiveness in people consuming antipsychotic medication.

Data from our own Spanish research (Untie Programme) shows that 67% of patients with dementia take antipsychotic medication and that 97% of antipsychotic medication is consumed by patients with documented cognitive impairment. According to a study carried out by Dr Banerjee, it is estimated that only 20% of these prescriptions in the United Kingdom (UK) correspond to a correct treatment, the rest being considered as inappropriate use with a restrictive purpose.Dr. Banerjee highlighted the higher morbidity and mortality caused by these drugs in people with dementia.

Finally, the sum of the effects of restraint on the health of the patient leads to a substantial loss in the functional autonomy of the patient which can be irreversible. In some cases, where the patient is especially fragile, the effect of the restraint can be catastrophic.

Ultimately, restraint hampers the necessary mobility of the person to a greater or lesser degree, impeding their normal development and the preservation of their bodily functions.

Use it or lose it: true for *brain* and body

5.Consequences of the use of restraint for the professionals and for the caring organisations

Professionals renounce other clinical practices when they resort to the use of restraint, which means an impoverishment of their work and a serious limitation in their professional development. The "Untie Programme" in Spain reached this conclusion when we carried out studies in facilities using restraint to identify and analyse the factors which influence this. In these exhaustive interventions in the facilities (72 in total), we observed a repetitive pattern:

- The registration of falls is limited.
- The analysis of falls is insufficient and does not take into account all the factors which may help to prevent falls, especially environmental and organisational factors.
- A structure for the management of falls and the use of restraint does not exist (e.g. committees, multidisciplinary teams).
- Many behavioural symptoms of dementia are not evaluated. They are only evaluated when there is a significant impact on other residents and on the carer's work.
- Non-pharmacological therapies for the management of people with dementia and their behavioural problems "symptoms" are not used.
- Strategies for the rationalisation of the use of psychotropic medication are not applied.
- Strategies for the rationalisation of polypharmacy are not applied.
- The use of psychotropic medication and the management of behavioural problems/symptoms are not dealt with in an exhaustive way at interdisciplinary meetings. Staff decisions on the use of restraint are strongly influenced by the staff in direct contact with the patient (i.e. by the nursing assistants).
- There is an important failure in delaying the onset of incontinence in people with dementia.
- Protocols for falls and restraint are not consistently applied.
- More practical instruments for evaluating the functionality of people with dementia and their symptoms have not been widely implemented, and if they are being used, they are used badly e.g. FAST (= Functional Assessment Scale).
- No information about what the person with dementia is likely to experience is given to families in advance so that they can make decisions in advance.
- Scarce promotion of mobility, strength and muscular resistance.
- There is a poor system of detection of significant changes in the condition of the patient and "sentinel events" (i.e. which are cause for alarm), and adequate response to these events.
- The training of professionals is not adequate or suited to the real needs of the patients.
- There is poor ethical reflection on the use of restraint.

All this allows us to conclude that clinical practice on the part of the professionals in the interdisciplinary boards is of poor quality and caused by the use of restraint which does not allow professional development and the acquisition of experience.

The use of restraint can also have an impact on the emotional state of the professionals, such as *anxiety*, frustration and feelings of guilt. More specifically, we can say from our research that there were more cases of burnout (evaluated by the Maslach scale for health professionals) in facilities where restraint was used most.
Equally, care organisations, where the policy is to restrict their patients, reject the development of creative organisational strategies to increase the safety of their residents, and they are not aware of environmental and technical aspects which promote the safer mobility of their patients. In our research in the facilities, we observed serious deficiencies in the passive physical security, things such as free access to dangerous zones, poor lighting, a high number of obstacles in walking areas and overcrowding in certain areas. Regarding the furniture, there were few options to adapt the heights of the beds to the needs of each person, hardly any variety of seats, which was insufficient for the different characteristics of the patients.
The organisations that use restraint may suffer a greater legal insecurity and they may also face greater conflict with the families of the residents. We believe that these negative effects are due to the false perception of safety that restraint gives, with the consequent relaxation of the necessary surveillance and accompaniment that professionals should provide, and the consequent mistaken conviction of family members that by using restraint their loved ones are safer. A review of Spanish case law shows a high incidence of lawsuits for cases of negligence, lack of diligence and abandonment of care.

6.The use of restraint for convenience

The use of restraint for convenience can be defined as a use which results in the reduction of the workload and less effort for the employees in the facility, but a use which does not target the well-being of the person with dementia. The use of restraint should never cover up a deficiency, lack of professional capacity or organisational defects in the facility.
When we analyse the affirmation “more staff are needed to avoid using restraint” (a very prevalent idea in society), we deduce that there is a certain universal tolerance of restraint as it is believed we can save on human resources using this practice. All society should reflect on this. Fortunately, this affirmation is based on the myth that one cannot avoid the use of restraint without increasing the number of staff.
In studies carried out by the Spanish Untie Programme, we have found that all restraint used is used on a daily basis, and that the patterns of its use correspond to the convenience of the facility or the staff.
It is interesting that precisely when professionals try to use restraint for the shortest time possible, they show that its use is for convenience or because of organisational deficiencies of the facility. This is the case for restraint used only at night, for restraint used only for a short period of time every day at the same time, for that used only in one type of chair and not in another, or for that used only in some places and not in others, or which are repeated every day under the same circumstances. To show that they are not being used for convenience, they would have to explain why they are needed only in bed and not during the day, or why they are only needed at certain times of the day, and not at others, and why they are needed every day at the same time, or why they are needed only in certain places and not in others. All these uses of restraint could be avoided if

timetables and the organisation of work were modified, if beds and chairs were adapted, and if the rules of the facility and its environment were changed.
Certainly, it is a false convenience because it may seem cost effective in the short term but the consequences of the daily use of restraint include more work, complications and cost to the organisation.

7. Resurgence in the use and development of new and subtler forms of restraint

There are references to this phenomenon, a resurgence in the use of restraint in facilities that have been followed for a long time after its reduction. We learned a very important lesson in our own "untying" experiences in Spain. The first 44 "interventions" were carried out with a modest objective; the objective was to reduce the prevalence but not to eradicate the use of restraint. Experience showed us that during this process of reduction, they looked for other subtler means of physical restraint, or medication with restrictive potential other than the conventional psychotropic drugs used to restrain and what is most interesting is that after months of achieving the maximum possible reduction in the use of restraint, there was a resurgence, and that after 6 months, the prevalence of restraint was similar to what existed at the beginning. At the end of 2009, we began to work with an attitude of zero tolerance in order to achieve restraint-free facilities, and at the end of 2012 we have 28 successes. We think that mentalities do not change until the facility has worked for some time without restraint, and that they do not remain free if this mental change does not happen.

> A great skepticism prevails on the possibility of working without the use of restraint. SEEING IS BELIEVING. Professionals only believe it when they manage not to use restraint themselves for some time.

And so preventing the resurgence of the use of restraint is assured when the facility eradicates all restraint and continues to do so for at least 3 months or until it consolidates the necessary mental change. It is also necessary that the facility is habilitated for this, and that there are no legal threats or social pressures that could change the attitude of zero tolerance.

> In order to prevent the resurgence in the use of restraint or new forms of restraint, a favorable context is necessary which is conducive to restraint-free care.

While the convenience of third parties continues to be considered acceptable and there is still pressure on professionals which generates fear and conflict in professionals in relation to possible accidents in the patients, a resurgence in the use of restraint occurs and it stimulates the development of new, subtler and masked forms of restraint.

8.The use of restraint is a practice which generates ethical and legal conflicts. How much safety can be demanded?

In Spain, the principal cause of ethical conflicts for professionals working in nursing homes is the use of restraint. There is also supporting evidence of this in studies carried out in other countries. In one wide-scale study involving 577 nursing staff into the abuse of older people, those interviewed widely agreed that the abuse in the form of physical restraint was the most frequent form of physical abuse.
On the other hand, we detected in our work in Spain that the directors of the facilities and the doctors were afraid of the possible legal consequences for them should the residents come to any harm, and we also found that there was a more hostile attitude amongst the family members of the patients in the facilities where they used restraint than in the restraint-free facilities.

> The use of restraint creates a false sense of greater security

Although the staff in the nursing homes experience a tension between their duty of care and their duty to respect the human rights of the residents, the Untie Programme has established that once they see that nothing happens to the patients by removing the restraint, they feel calmer and gladly accept to work without restraint. SEEING IS BELIEVING.

> Restraint-free facilities in Spain show us that the use of restraint can be avoided and that this is safe for the patients.

According to our experience, the stress experienced in removing the restraint (i.e. untying) lasts between three and six months.
Professionals who have a non-restrictive attitude ask the same contradictory question ("How much safety is safe?") as their colleagues and the relatives of the patient, and they also share the arguments which provide an answer to this question in every case of doubt. This avoids ethical conflicts and prevents lawsuits arising from the decision to avoid the use of restraint.
How much safety can be demanded?
The Programme has established a minimum safety requirement required for centres that eliminate the use of restraint. The minimum security conditions required are:

- The centre responds appropriately to avoid damage in all cases of serious and imminent threat to the life or integrity of oneself or others.
- In the centre, the incidence of hip fractures should not exceed 1.5 in 100 falls.
- In the centre, the incidence of serious head injuries (requiring transfer of the person to the hospital) should not exceed 0.5 in 100 falls.
- In the centre, people with dementia should not have a prevalence equal to or above 3% (every day for 7 days) of serious behavioural problems such as verbal abuse, physical abuse, socially inappropriate or harmful behaviour or the refusal of care.

Based on the studies of incidence and prevalence of these problems, and on the basis of our database (i.e. that of our Programme), of the facilities that are using physical restraint on a daily basis, the incidence of hip fractures is 3 to 5 in 100 falls, the incidence of serious head injuries is 1 in 100 falls, and the prevalence of serious behavioural problems is over 8%.

9.Restraint-free facilities. Prevention is better than reaction

There are no lives without restrictions and this is also the case for people with dementia, but there are nursing homes which do not apply physical or chemical restraint. These are the restraint-free facilities. In Spain there are 28 centres, verified by us, that have eliminated all use of restraint.
If in a nursing home, they do not apply a new means of restraint, apart from those already having been applied, it will be converted into a restraint-free facility in a given time. This is a strategy of prevention.
When we help a facility to become a restraint-free facility, we propose that they arm themselves with the necessary strategies to avoid applying a new means of restraint, that it would be useful for them to mark the date when they can begin to avoid using restraint completely and in the meantime, they must start a process of eliminating restraint already used in the facility. The professionals themselves, after a period of training and obtaining experience, admit that it is easier to avoid using new means of restraint than eliminating that which they have been using. Prevention rather than reaction. After a period of using restraint on a daily basis, many people lose their autonomy. Not only can this be irreversible but it can make it even more difficult to deal with them without using restraint. It is a vicious circle.
Restraint-free facilities are so (i.e. restraint-free) because the professionals and manager have adopted an attitude of zero tolerance, sometimes even going against the opinion they used to have on this issue.

> We now know that maintaining a certain degree of tolerance towards the use of restraint results in failing to achieve its total elimination, although it is possible.

The facilities where we are carrying out our research are facilities which once used restraint and managed to eradicate its use completely through effort and a suitable strategy. These facilities have shown us that a change of paradigm is possible and necessary to maintain restraint-free practice. They also show us that it can be achieved without increasing staff numbers, without conflicts with the relatives of the patient and without a big incidence of complaints or lawsuits. We have also seen more effective formulas in achieving it that are safer than using restraint, taking as a safety indicator the incidence of fractured hips. There have been improvements in many other aspects as we will see in the following point.

10.Zero tolerance is an engine of improvement. Everyone wins

In order to acquire an attitude of zero tolerance, one must face the challenges that people with dementia pose every day with more knowledge, better strategies and more creativity. Apart from this, new experiences improve the

capacity of the professionals. When they work like this for a time, they gain greater respect from others. They improve their knowledge about the prevention of falls, dementia and its BPSD, handling the environment, technical aids, non-pharmacological therapies, the management of psychotic drugs and polypharmacy. Experience is acquired by dealing with these problems without the use of restraint, and developing strategies to prevent them. As the interdisciplinary teams are improved in this respect, they become more capable of working without restraint in a safe way.

Professionals gain knowledge and experience and they also feel happier in their work (burn-out decreases). The working atmosphere in the facility is better (the loyalty of staff increases and they would now not like to go to a facility where they have to use restraint again).

The people who work in direct contact with the patients also improve their knowledge of dementia and its symptoms. In interviews carried out in the framework of the Programme, some of these professionals expressed their experience of discovering the people hidden behind the restraint, stating for example, “A lot of people began to talk and walk again”. These professionals also improved the organisation of their work, which became more flexible and individualised with the aim of adapting to the peculiarities of each resident.

We also discovered that some professionals, on hearing about these facilities expressed an interest in working in them, with the idea that they could develop professionally in these restraint-free facilities without the obstacles imposed on them by having a high number of restrained patients.

It is not only the professionals who win. Families are also more satisfied (they have a more fluid and frequent contact with the professionals in the facility).

The patients with dementia themselves are the ones who benefit the most, with clear indicators of improvement in their physical and mental conditions, and a progressive increase in their autonomy. The prevalence of serious behavioural symptoms decreases which leads to a better atmosphere in the facility (the patients are calmer without restraint).

Facilities improve their environmental security, which gives more mobility to the patients, something that is especially interesting for those with preserved autonomy, or who can recover.

The facility itself improves its social image as an institution. There is a system of accreditation for restraint-free facilities in Spain. Everybody knows which facilities have an accreditation as a restraint-free facility.

CONCLUSIONS

The condemnation of the use of restraint on people because of their illness should generate a reaction which gives hope to people with dementia. We call this reaction “Zero Tolerance” and it is based on prevention.

There are no lives without restrictions. This is also the case for people with dementia, but if you can avoid direct physical and chemical restraint (which is a great achievement for the respect of the person), then you have a moral duty to do so.

We now know that maintaining a certain degree of tolerance towards the use of restraint makes its elimination difficult to achieve. Restraint-free facilities are showing us that the complete eradication of this practice is possible and that exceptions are rare.

The carer should evaluate the risk associated with mobility and accept a certain degree of risk as an essential part of good care.
In general, the prolonged use of restraint usually corresponds to a use for convenience in the world of care for people with dementia and for that reason, it is the moral duty of professionals to eradicate this practice.
Zero tolerance regarding the use of restrains is a preventive attitude. It is based on the rule of not considering restraint an option. Restraint is reserved for extreme situations which generally do not occur, if an effective prevention of the reasons to restrain has been implemented. If you apply restraint in an extreme situation, it should never be continued beyond this isolated episode. The exceptions are when the restraint is used in order to save a life, or if a person's integrity is threatened in a serious and imminent way. These cases are rare in practice and the normal thing is to work without having to use restraint (we have cases in facilities in Spain where they have managed not to use restraint for more than two years).

Zero Tolerance of Restraint: A Winning Strategy. "Zero tolerance" is quickly becoming the new paradigm in restraint prevention.

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ARGUMENT 2

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ARGUMENT 10

Zero tolerance is an engine of improvement. Everyone wins

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