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# PEOPLE WITH AUTISM SPECTRUM DISORDERS (ASD) IN EMERGENCY

## VADEMECUM FOR THE RESCUER



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*This vademecum, prepared by the Provincial Command of the Pordenone Fire Department in collaboration with the Children and Autism Foundation ONLUS, is aimed at operators who have to intervene in emergency situations, to facilitate their activities in the face of people who have a very special disability such as autism.*

*It expresses, first and foremost, the willingness of the Corps to take charge of a need perceived by those who assist these people, but it is also further proof of how firefighters have always been close to those in difficult circumstances and, with their characteristic sense of humanity and generosity, combine expertise and solidarity, professional skill and shared needs and feelings.*

*This is in the knowledge that only by removing the obstacles that prevent the full exercise of rights will we promote the social inclusion of people who are disadvantaged and who, as such, need protection.*

**Maria Rosaria Lagana**

Prefect of Pordenone



*In carrying out their institutional duties, firefighters may encounter situations where people with autism are present. In order to protect their safety, it is necessary to know some of the characteristics of the Disorder and some of the strategies and modes of operation to be adopted to facilitate a proper relational approach.*

*The objective of this vademecum is to provide useful guidance on the knowledge of the problem and how to act in case the rescuer has to operate in the presence of these people, whether children or adults.*

*However, such guidance can serve as a reference not only for firefighters but also for other workers who in various capacities interact, even as a function of their duties, with people with autism.*

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# WHAT IS AUTISM

First, it is not a single disorder, but a group of disorders of a neurobiological nature more correctly termed Autism Spectrum Disorders (ASD) whose symptoms manifest early and persist throughout the course of existence.

There is tremendous variability both in the presentation and severity of major symptoms and in relation to non-ASD symptoms, such as cognitive ability, expressive language ability, mode of onset, and medical and psychopathological comorbidities.

Although in the different clinical manifestations there is the presence of atypical behavioral patterns that can be summarized as (DSM-5, 2013):

- A. Deficits in communication and social interaction
- B. Behaviors and interests, narrow and repetitive.

Compared to other types of disabilities that often take the form of lower functioning (e.g., motor for physical disabilities, health for chronic diseases, etc.) but retain a neuro-typicality of thinking, Autism Spectrum Disorder presents as a different mode of functioning. Specifically, social, communicative and relational deficits are due to the inability on the part of people with autism to "understand" how the world of others works. They lack insight not only into the social world but also into the succession of events. This is why they struggle to cope with changes in routine and the unexpected, to cooperate and to have initiative in solving even trivial problems, such as moving out of a danger zone; for the same reason they may get into crisis over waiting or having to wait their turn or other similar situations.

People with autism do not have the ability to put themselves in each other's shoes or understand that people react to each other's behaviors, so they do not know how to connect a reaction that

see in the interlocutor with their own behavior, they do not understand why others may be angry, sad, happy or seek social contact.

There is evidence that sensory stimuli are also processed somewhat differently by people with autism than by the neurotypical (NT) population. A siren, an object "out of place" may lead them to a fit of agitation; an excited tone of speech, a noise even completely bearable to us, may cause them to plug their ears and escape to another place.

All this can cause people with autism to live in a perpetual state of anxiety or anguish not being able to understand whether the people nearby, their behaviors and approaches will be friendly or hostile, how and when unpleasant or difficult situations will end or even if they will end at all. Anxiety that may result in obsessively repeated behaviors, sequences of stereotyped movements, or even self- or hetero-aggressive attitudes.

Verbal language is not always present, and even when it is, its use may be bizarre or seemingly meaningless. Difficulties may relate not only to the production of language but also, and more importantly, to its comprehension (and thus even people with autism who express themselves very well may have difficulty understanding the meaning of what is being said to them, particularly when using language rich in nuance, metaphors, irony, etc.). For the same reasons, they may have difficulty when faced with articulate questions or questions containing "why?", which they may answer inappropriately or with repetition of the question itself.

Not infrequently associated with the disorder are mental retardation and conditions



medical of other kinds (for safety purposes in particular, keep in mind that there may be in comorbidity epileptic pictures).

Prevalence is far from rare: the most recent data from the Center for Disease Control and Prevention Epidemiology Program Office reports 1 case per 68 children in the 8-year-old age group (CDC, 2014).

## THE PERSON WITH AUTISM AND THE EMERGENCY

The characteristics of autism described so far, already disabling in everyday situations, can become real obstacles in the face of emergencies, provoking unpredictable, bizarre, or even aggressive behavioral reactions that can jeopardize their own and others' safety.

Therefore, the following information and guidance will help us understand how to recognize a person with autism and, most importantly, what to do in an emergency situation, what are useful strategies, and how to communicate.

Let us not forget that, in parallel with the training of rescuers, it is important to work ahead of time to prepare the person with autism to best cope with an unexpected or difficult situation. Similarly, it is also important for family members and caregivers to work together to always tell the rescuers in advance, whenever possible, that they will be in the presence of a person with autism; this will allow them to prepare to take the best measures.

### ***What if you woke up one day on Mars.***

*Imagine that you have landed from a spaceship on an unknown planet where there are many beings that look entirely like you talking, moving, laughing and crying, but, alas, for reasons unknown to you.*

*You do not know their language, but you do not understand their gestures either. It seems to you that they move according to certain rules completely unknown to you, you can't intuit practically anything about that world, however you sense that it could be very dangerous, you can't read in the faces of those beings whether they will be hostile or leave you alone, so you feel loaded with anguish, always in a situation of alarm.*

*You have very developed senses, much more than theirs, so you hear much more of noises, smells, tastes. Your sight is so acute that you see details that they don't even perceive, and some of these worry you greatly, while they leave those beings completely unconcerned: sirens, whistles, glares, even an unusual outfit or a perfume you've never smelled can put you on edge, anything that changes in the environment you thought you were beginning to know puts you back into a state of unease.*

*Unpredictability is the worst enemy, and everything you have not yet experienced on that unknown planet is an unforeseen for you. And what's worse is that the inhabitants of that planet don't realize that you are an alien and so they address you by talking to you, gesturing at you, pressing you, they don't understand why you are so frightened, they don't understand why you don't behave like them, they don't understand why you don't respond, they can only see that you appear or make strange gestures, they don't understand why you make repetitive noises, why you move objects or put them back in their place. This is your condition. This is being autistic!*

*It is not just a figment of the imagination, Temple Granding, a scientist with autism (1), and Clare Sainsbury also with autism, have called themselves one "an anthropologist on Mars" (2), the other a "Martian on Earth."*

*Here, then, is where imagining the sense of estrangement that we, too, might feel by being catapulted onto an alien planet-and thus into a place whose workings, rules, and customs we do not know, nor can we intuit, can be helpful in trying to understand the kind of condition experienced by an autistic person, the disorientation, the difficulties in understanding the code system we all use to communicate and the distress that comes with it, but above all it should be a stimulus to become a little more careful in recognizing these "guests" of ours and to welcome them with courtesy and kindness.*

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1 Autism can have many facets and levels of severity. It is possible to find people with very severe and disabling autism, and others who, while having relational difficulties and different ways of processing thought than neurotypical people, have a high "level of functioning" and cognitive abilities even above the norm, such as precisely Temple Granding.

2 Definition that Oliver Sacks in 1995 borrowed to title a book that would later become a classic of neuropsychological literature.

## CAN I RECOGNIZE A PERSON WITH AUTISM BY SEEING THEM?

People with autism have no particular physical characteristics that are useful in identifying them. In certain cases (not all) they may exhibit attitudes such that we may assume that we are dealing with a person with autism, for example:

- Motor clumsiness and some rigidity in movements;
- Gait on toes or abnormal gait;
- presence of motor stereotypies (flickering or clapping of hands or fingers, repeated gestures and movements, tics, etc.);
- difficulty making eye contact;
- Absence or poverty of facial expressions;
- Absence or poverty of communicative gestures;
- Emission of sounds, shrieks, sometimes repetitive or out-of-context snickers;
- Stereotyped verbal manifestations (repeating words or phrases out of context);
- seem indifferent to each other's presence or approach the person too closely perhaps to observe/touch/smell a detail.

# CAN I RECOGNIZE A PERSON WITH AUTISM BY THE WAY THEY INTERACT WITH ME?

It is much easier to recognize individuals with autism the moment you interact with them, especially if you pay attention to the following details:

- may seem distant or indifferent to others or conversely be too expansive (touching you, getting too close, asking questions inappropriate to the context, etc.);
- They may have difficulty interpreting your gestures or speech;
- may answer questions inappropriately or not answer them at all, or answer them by repeating them;
- they may give you unreliable or contradictory answers especially if the question you ask them is complex or contains connectives such as "and," "not," "or," "if" (e.g., when faced with a proposition such as "do you want to stay here or go home?" they may answer "home" and immediately afterwards, if the question becomes "do you want to go home or stay here?" answer "stay here," echoing the last word); they may take similes or metaphors literally;
- in conversation may not be adherent to the relational context and lead you toward their own interests;
- may avoid eye contact or, if there is, it may still seem abnormal (fleeting or too fixed);
- may retract if you approach or try to have physical contact;
- may have abnormal sensory reactions, such as sniffing or touching, being bothered by certain noises or attracted to certain details, light plays or details of objects;

- may have bizarre reactions to your tone of voice, gestures or facial expressions, showing that they do not understand them;
- may apparently show no emotion with respect to happenings that involve them;
- may get annoyed if you press them or if they have to wait or if there are changes in their routines or unforeseen events happen;
- can have self-injurious or hetero-aggressive reactions if the stress level is high;
- may have difficulty understanding the consequences of their actions or events and risk putting themselves in danger.

## **DURING AN EMERGENCY, PEOPLE WITH AUTISM MIGHT REACT IN AN UNUSUAL OR BIZARRE WAY, FOR EXAMPLE:**

- Not recognizing danger and being strangely calm or indifferent;
- on the contrary, fail to control themselves and have self- or hetero-aggressive attitudes or enter into psycho-motor agitation crisis;
- Entering a strong state of anxiety;
- not identifying the rescuers as such and thus becoming frightened, fleeing at the sight of them and not cooperating;
- give rise to verbal or motor stereotypies (loud rocking, vocalizing, banging objects, etc.);

- wanting to complete the task in which they are engaged rather than running away (in which case consider whether there is time to let the task finish, within a certain time limit, rather than abruptly stopping it);
- hide in a place that gives them security but instead may not be safe for the situation at hand;
- go looking for an object of interest or consolation (e.g. it may be that instead of running away they try to go retrieve a game, dvd, etc.).

## WHAT TO DO IF THE PERSON STARTS SCREAMING TO ESCAPE FROM A PLACE OR SITUATION?

During an emergency situation, a person with autism might scream and flee not necessarily, or not only, because he or she is frightened by the danger itself but also because he or she is bothered by elements that we would judge as "secondary" or unimportant (the sound of a siren, noises or lights, the interruption of a routine, the arrival of help itself).

The moment a person starts screaming, flailing and trying to escape the rescuer can be helpful:

- if there is an opportunity to get help from family members, prefer an approach mediated by them;
- If the rescuer is bare-faced, maintain a calm expression, remaining calm and still;

- Move calmly without sudden movements and staying in front of the person;
- do not immediately try to contain the person physically, but stand in front of his or her visual trajectory, hold out your hand waiting for the person to grab it. If possible, try to identify a personal object to use as an attractive element to be followed;
- Explain the situation in simple language and anticipate in small steps what will be done;
- Prefer communication of analog gestures (those that refer directly to meanings);
- if you have visual communication aids (such as a picture, as we will see below) use them by accompanying them with gestures;
- Do not insist on verbal language that can be confusing, speak little;
- Do not use excited tones of voice;
- if the dangerous situation is such as to warrant coercive methods, prefer the least traumatic modes possible.



# WHAT CAN BE USEFUL AND WHY IN AN EMERGENCY

The following are proposed tips on what to do in emergency conditions where people with autism are present. For each advice, it is possible to consult the relevant rationale explained from the characteristics of autism, which are recalled from time to time.

## It can be useful:

- Get the person's **attention** and then prepare him or her before communicating something to him or her: try saying his or her name (if you know it) or a preparatory expression: *look, listen, pay attention, be ready, etc.*
- **Observe the person** carefully because he or she may also be injured in a major way while not complaining or manifesting pain.

## Because:

- People with ASD may be absorbed, distant, and uninterested in other people. Calling attention before a communication helps them focus on the other person.
- People with ASD may react in uncommon ways to painful stimuli (e.g., they may experience mild grazes as very painful and conversely not complain about major injuries). They may not be able to recognize and communicate *where* pain is coming from

### It can be useful:

- **Explain** one's actions, showing them on another or on oneself.
- Use **simple, concrete language** consisting of **short, clear sentences** (avoiding metaphors and idioms).
- Use a **low, soft tone**

### Because:

- The person with ASD may not be able to infer what is happening from the context, may not understand what is being done. Explaining the actions being taken, even those that seem obvious, promotes understanding and thus collaboration.
- The verbal channel for the person with ASD is impaired: he or she may not use or understand language well. Similarly, the person with ASD has difficulty understanding metaphors, idioms, irony or sarcasm and tends to take everything literally. Therefore use short, simple and unambiguous sentences (e.g., say "let's go outside" instead of "come with me we'll get to safety").
- Some people with ASD cannot tolerate loud sounds. Speaking softly, calmly, and in a low voice helps them focus, decrease anxiety, and helps reduce "sensory bombardment."

### It can be useful:

- Respect their need to **maintain distance** and **avoid physical contact** when not strictly necessary.
- Try to **position yourself with your face at the subject's eye level**, making sure as far as possible that he or she is paying attention to us, but not demanding eye contact and, indeed remembering that the lack of it does not mean that the subject is not listening.
- **Anticipate** what you are going to do with a few simple words, particularly before touching the subject (don't catch him off guard, don't assume he will infer from the situation what is about to happen, warn if you are about to pick him up, etc.).

### Because:

- Many people with ASD need a "social distance" of safety. They may also dislike physical contact because of sensory disturbances (tactile hyper sensory). They may experience distorted or painful pressure or rubbing on the skin (in contrast, they may not experience pain in the presence of major injuries).
- People with ASD tend to shy away from eye contact. It may therefore be helpful to position themselves at face level to encourage interaction, but without forcibly demanding contact that they may not be able to implement.
- People with ASD have difficulty understanding the world around them, what is happening and what will happen. Anticipating, in a simple and essential way, what is going to be done to them, or with them, helps them know what to expect and thus encourages their cooperation.

## It can be useful:

- Where possible use some simple **pictures** to anticipate and explain what you are going to do. If possible order them in action steps: for example: I am inside the building - the firefighter escorts me out - then I will go home or another safe place. If pictures are not available it may be helpful to make a written list of the actions you will take (count to 3 - on 3 we leave - wait outside).
- If you do not have visual or written supports, think about what is the essential information to communicate (who I am, what is happening, where I am taking you) and **communicate it in an orderly and consequential way**. Possibly search the surroundings for objects or tools that can support the message.

## Because:

- The deficit in communication that characterizes people with autism means that they need verbal language to be supported with images (photos or drawings) or writing. Temple Grandin, a high-functioning autistic scientist, even stated that she "thinks in pictures" to emphasize how the visual channel is extremely more important to her than the verbal one.

- People with ASD have difficulty not only understanding long, complex sentences but also remembering the sequence of actions necessary to achieve a goal.

Depending on the level of severity of the Disorder, they may therefore have difficulty in personal autonomy and performing even simple tasks. It is therefore important to identify the basic steps of an action and communicate them one by one.

## It can be useful:

- Indicate verbally and/or visually **how and where** the rescue **procedures will end** (e.g., that at the end of the emergency you will go home, assuming the house is still there, or to another welcome place such as the bar or supermarket).
- If possible, in case a person with autism needs to be led outside, show a **photograph** of the outside of the building (taken at the time, with any tool, such as a cell phone) saying "I'll take you here."
- Accompany requests to leave, move, etc., with gestures (**physical prompts**) that are simple and clear and not unnecessarily reiterated, but without touching the subject (e.g., accompanying the "let's leave" indication with a single hand gesture indicating leaving by having the subject grab or put their hand on their shoulder, rather than pushing or pulling).

## Because:

- People with ASD have difficulty predicting what will happen and generalizing information. Telling them that at the end of an unwelcome thing they will be able to go home or at least to a reassuring place helps them reduce stress.
- Explicitly showing where you will go makes it more likely that the person with ASD will cooperate and follow you.
- At base of this suggestion are always the difficulties in understanding the language of people with ASD. Supporting a request with a simple, clear, unambiguous gesture helps the person understand what we are saying to them and what is expected of them.

## It can be useful:

- If necessary, to facilitate movement, accompany a request with the **promise of a reward** (if there is time and opportunity, ask the family member or caregiver what might be motivating for the person).

- **Reinforce appropriate behaviors in all cases.** For example, say "good" emphatically after the person has behaved properly.

- **Scan the actions by counting**, e.g. if the person does not move, count out loud "1- 2-3 WAY" and then accompany them to the exit. Equally if the person is to be immobilized with a procedure, you can say for example, "Now I have to put the collar on you, I count to 20 and it's over: 1, 2, ..."

## Because:

- Some times the implicit reasons for a request are neither sufficiently clear nor sufficiently motivating for a person with ASD. Similarly, "follow me because we'll get safe" may mean nothing to some people with autism. The promise of a reward, on the other hand, can be very motivating.

- Rewarding appropriate behavior with recognition, including social recognition ("bravo!"), may in some cases be pleasing to the person and prompt him or her to repeat the reinforced behavior.

- People with autism may have difficulty predicting the duration of events, which puts them in an anxious state. Giving actions and events a defined time dimension, including through the strategy of counting, can foster collaboration.

### It can be useful:

- Compatibly with the level of emergency, allow the person to carry an **object of interest**, a game, a garment, a ball, or any other manipulable object of interest to decrease anxiety or distract them.
- Compatibly with the level of emergency, if the person is doing a welcome or work-related activity use **strategies to indicate its end** rather than abruptly interrupting it (e.g., put two more puzzle pieces, count to 3, do 3 more jumps). Similarly where possible, i.e., where this does not impede emergency procedures, have the person evacuate along with the object with which he or she was engaged (e.g., take the child away along with the booklet he or she was leafing through).

### Because:

- People with ASD have difficulty managing anxiety, controlling themselves, and understanding situations. Having an object of interest helps them distract themselves, relax, establish a reassuring routine in the midst of an unexpected and chaotic context.
- Some people with ASD may react very badly when interrupted in the middle of an activity or routine. During the emergency they may also find it more important to finish what they were doing than to run away, failing to objectively prioritize the actions. Assigning a "formal end" to the action makes them agree to conclude it more easily. At the same time, being able to have an object of interest (e.g., a small booklet) can help fill waiting and reduce risk behaviors (wriggling and running away, not being able to wait, etc.).

### It can be useful:

- When possible, **move the person away from sources of noise** (remember that many people with autism have sensory disturbances and may poorly tolerate loud noises and lights). For the same reason, where possible, it may be helpful to **turn off** the **siren** near arrival.
- Once the neutral or otherwise safe space has been reached, pay special attention to ensuring that the person is **not left alone** and where possible **engage them in some activity** (holding something, counting, singing, etc.).
- Once taken outside, if possible have the person wait in a place that is not too chaotic and offer them music on headphones or booklets/magazines (it may be useful to **set up a small kit** to keep in the middle

### Because:

- Many people with autism may suffer from hyperacusis and poorly tolerate noises that are not normally disturbing to neurotypical people. It may also happen, on the contrary, that they appear indifferent to significant noises or to the call of their own name.
- Remember that people with autism may in many cases be unpredictable and may even attempt to return to the danger zone, being unable to assess the extent of the emergency or all the consequences of their actions. Trying to engage them in some action can help them keep anxiety under control and reduce problem behaviors.
- People with ASD generally have a poor tolerance for waiting that they cannot independently manage or fill with meaning and of which they have difficulty imagining the term. Music or certain objects



## It can be useful:

transport containing recreational items for use during waiting times).

- If you need to identify the person, try to ask or look for any **cards** with useful numbers (some people with autism may have a card in their wallet with parent or caregiver reference numbers, address, etc.).
- If taking the person to the emergency room, **alert the emergency room in advance** that the person has autism so that the necessary procedures can be activated.

## Why:

distractors can help them relax, stay engaged, attach meaning to waiting.

- Family members/caregivers may have provided the person with a card with useful contact information, and other basic information (e.g., "My name is .... I have autism. I do not speak. I suffer from epilepsy. I take the following medications...").
- Access to the emergency department of a person with autism can be very difficult for the person himself or herself, but also for health care providers. Alerting the hospital emergency department in advance of the arrival of a person with ASD can allow the best measures to be taken <sup>1</sup>

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<sup>1</sup> At Pordenone Hospital, for example, a Protocol for the reception at emergency departments of people with Autism Spectrum Disorders, defined together with the Children and Autism Foundation, has been in place for several years.

Read more: Raffin C., Copat O., Moscariello F., Dall'Amico R. and Filippini M. (2013) "I urgently need you, but I can't tell you! Intervention protocol for people with Autism Spectrum Disorder at emergency departments." Autism and Developmental Disorders, 2013/1.

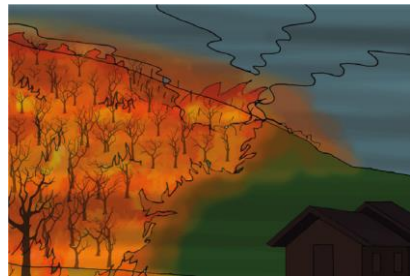
## IMAGES TO COMMUNICATE

As mentioned above, the use of imagery, to anticipate and explain what you want to do, is an important resource in dealing with a person with ASD.

The following are just a few simple examples with which a brief emergency communication can be structured. The ready availability of these images can be a strategic resource in managing a critical situation.



*Fig.1 - There is a fire in the building.*



*Fig.2 - There is a fire in the forest.*



*Fig.3 - There was an earthquake.*



*Fig.4 - A flood is occurring*



Fig.5 - Stop what you are doing



Fig.6 - Follow me, let's go outside



Fig.7 - I have to carry you



Fig.8 - Let's go to the ambulance  
in the emergency room

## "There is an emergency, we need to get out": Example of communication using images

In structuring the communication, the logical sequence with which to propose images is as follows:

1. Represent the situation that is arising and that you need to get away from. In this case, the proposed images represent only examples, but more effective, because they are more recognizable, would be photographs of the actual situation that can be taken with a cell phone as you arrive.

2. Communicate the need to stop all activities immediately. This can be done by displaying the "STOP" symbol and using a simple gesture as shown in Fig. 5

3. Show the action to be taken after finishing the activities that were being carried out. For example, "follow me to the door" as depicted in Fig. 6.

The following, for example, represents a situation in which it is necessary to evacuate a burning building by following a firefighter.



We communicate the emergency: "There is a fire in the building."



We communicate that it is necessary for the person to stop what they are doing, "I count to 3 and then that's it: 1, 2, 3 is enough."



We inform that è necessary to evacuate from the location, "Follow me, let's go outside."

## A special case: door opening intervention

The sequence of images that follows represents a particular and fairly frequent type of intervention: opening the door of a dwelling. The first shows the difficulties in opening the door, the second and third the action the firefighter takes to gain access through the window, but seen from the outside, while the last two the same action seen from inside the dwelling, through the glass.



Assuming that there is a person with autism inside the home, in order to predispose him or her to accept the intervention without enacting negative behaviors, the sequence of images can be proposed simply by passing them under the door.



Graphics and layout are by Redlime Srl. The cover image is by  
Elisabetta Schiavone.

*In carrying out their institutional duties, the fire department, as well as other agencies or facilities that operate in various capacities in the area, may encounter situations where people with autism are present, requiring special skills to relate to them, as well as implementing some simple operational methods to protect their safety.*

*The objective of this vademecum is to provide simple guidance in this regard starting from the knowledge of the problem to the proposition of correct intervention methods to be implemented in case the rescuer has to work with these people, both children and adults.*



FOUNDATION  
Children and Autism NGO



PORDENONE Provincial Command