

Autism Catatonia Evaluation (ACE-S)

This resource should be used in conjunction with the book from which it originates.

Shah, A. (2019) *Catatonia, Shutdown and Breakdown in Autism: A Psycho-Ecological Approach*.
London: Jessica Kingsley Publishers

Description

The Autism Catatonia Evaluation (ACE-S) has been developed by Dr Amitta Shah, consultant clinical psychologist in clinical practice. It is a framework for a systematic assessment and evaluation of catatonia manifestations in autistic children and adults. It can be used by anyone involved with an autistic individual in whom catatonia, shutdown and/or autism breakdown are suspected or as a screening tool for these aspects during other mental and physical health assessments. Amitta Shah is happy for people to photocopy ACE-S as a full document and use it responsibly with acknowledgement. Please do not photocopy or circulate any part-section on its own.

Uses

The ACE-S can be used for the following purposes:

- to guide assessment, recognition and diagnosis of catatonia, shutdown and breakdown in autistic individuals
- to describe and evaluate catatonia manifestations in autistic individuals
- to establish baselines and monitor progress
- to plan strategies, support and services and inform care plans or research purposes.

Instructions and caution

1. The ACE-S is not a quick diagnostic checklist for categorical assessments, and it is not suitable for quantitative evaluation. It is a dimensional framework for collecting information in a systematic way to build up an overall picture of the manifestations of catatonia, shutdown and breakdown in autistic individuals.
2. The ACE-S is not suitable for a direct assessment of the individual at a given point in time. It cannot be used to elicit the information by interviewing the person concerned or getting them to demonstrate the catatonia manifestations. Users need to be aware that there can be a lot of variation in the amount of difficulty shown by the individual on different days and in different situations. Thus, it is essential for users to get information about the individual from a variety of sources to get a full picture.
3. The ACE-S should be completed by using information from individuals – parents, carers and teachers, and so on – who have known the person and are able to give an overview of their functioning, deterioration and difficulties in different situations. This can be supplemented by information from direct observation of the individual in different settings, video footage and psychological assessment to build up the whole picture. Information from multi-disciplinary assessments such as speech and language therapy assessment and occupational therapy assessment can also be useful to supplement the information for particular sections.

SECTION A – DETERIORATION (INDEPENDENCE, SPEECH, ACTIVITY)

This section (together with Section B) is crucial for diagnosis.

Not be used as a checklist but to build up an overall picture.

Evaluate if there is a **change** and **deterioration** in the individual compared to previous levels of functioning and independence in the following areas:

1. Slowness

Is the individual showing obvious and noticeable slowness in movement, speech or in responding verbally or actively to an instruction?

Previous level

Current level

2. Self-help/personal care skills

(getting up, washing, personal hygiene, continence, dressing, eating)

Previous level

Current level

3. Independence

(occupying self, going out, carrying out activities)

Previous level

Current level

4. Mobility

Previous level

Current level

5. Speech (fluency, flow and volume)

Previous level

Current level

6. Level of activity

Previous level

Current level

7. Evaluation and brainstorm box

Make notes about possible time of onset, timeline and possible psycho-ecological factors which could be causing stress, distress or non-coping.

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SECTION B – MOVEMENT DIFFICULTY AND SHUTDOWN

This section (together with Section A) is crucial for diagnosis.

Not be used as a checklist but to build up an overall picture.

Evaluate if the individual is showing any of the following. The difficulty should not be fleeting but last at least five minutes, or the person needs an external prompt to move on or complete the action.

1. Stopping/freezing mid-action

Description.....

Frequency.....

Length of time (longest noted).....

2. Getting stuck

(e.g. getting out of bed, chair, car or toilet seat; walking)

Description.....

Frequency.....

Length of time (longest noted).....

3. Getting stuck at transitions

(e.g. door thresholds, stairs, kerbs, escalator)

Description.....

Frequency.....

Length of time (longest noted).....

4. Eating difficulties

(taking long, difficulty with fork and knife, chewing and swallowing difficulty)

Description.....

Frequency.....

Length of time (longest noted).....

5. Getting stuck in postures

(unusual postures, crouching, kneeling, etc.)

Description.....

Frequency.....

Length of time (longest noted).....

6. Prompt dependence

(verbal or physical prompt needed to move, initiate or complete action or activity)

Description.....

Frequency.....

Length of time (longest noted).....

7. Shutdown

(can affect individual in different ways – e.g. withdrawing totally from the external environment, curling up in a ball, inability to move or respond to anything external, non-communicative, or only able to engage in self-initiated repetitive actions and unresponsive)

Description.....

Frequency.....

Length of time (longest noted).....

SECTION C – MOVEMENT AND BEHAVIOUR ABNORMALITIES

*These may occur together with items in Section A and Section B but are not diagnostic of autism catatonia in themselves.
They are useful to note and describe as part of the autism catatonia picture.*

1. Posture and movement abnormalities

(e.g. twisting of neck, head, upper torso, grimacing, uncontrolled dystonic movements, shaking, tremor, etc.)

Description.....

Frequency.....

Length of time (longest noted).....

2. Complex sequences of repetitive movements

Description.....

Frequency.....

Length of time (longest noted).....

3. Other miscellaneous movement abnormalities

Description.....

Frequency.....

Length of time (longest noted).....

4. Episodes of uncharacteristic inappropriate behaviour

(catatonic excitement)

Description.....

Frequency.....

Length of time (longest noted).....

SECTION D – OVERLAPPING CATATONIA/AUTISM FEATURES

These are characteristic features of autism which overlap with catatonic features. The presence of these features is NOT diagnostic of autism catatonia. These are useful to note and useful for the overall diagnostic picture if these occur for the first time or if there is marked deterioration in severity/frequency.

1. Movements

(e.g. odd gait, odd hand postures, rocking, grimacing, mannerisms, complex repetitive movement such as spinning)

Description.....

Frequency.....

Time of onset.....

2. Speech and vocalisation

(e.g. immediate and delayed echolalia, repetitive noises and vocalisations)

Description.....

Frequency.....

Time of onset.....

SECTION E – AUTISM BREAKDOWN

Evaluate if the individual is showing autism breakdown in addition to the autism catatonia. This will need a qualitative judgement based on the overall picture of the following phenomena.

1. Exacerbation of autism

a. Increased social withdrawal, isolation, avoidance of social situations

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b. Increased communication difficulties

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c. Increased repetitive and ritualistic behaviour

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2. Decrease in tolerance and resilience

(easily disturbed, irritable, angry)

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3. Increase in 'challenging' behaviour

(e.g. self-injurious behaviour)

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4. Decrease in concentration, focus

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5. Decrease in engagement and enjoyment

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SECTION F – SECONDARY DIFFICULTIES

This section is not for diagnosis. It is for evaluating the secondary effects and can be used for planning support, services and monitoring progress.

1. Effects on independence

Description.....

2. Effects on occupation

(school, college, job, training, activities)

Description.....

3. Mobility and muscle wastage

Description.....

4. Medical and physical problems

(e.g. severe weight loss, difficulty passing urine, distorted breathing)

Description.....

5. Effect on quality of life

Description.....

6. Effects on parents, family, carers

(e.g. stress, inability to work, go out, etc.)

Description.....