

INSTRUCTIONS FOR COMPLETING THE AUTISTIC COMMUNICATION TOOL (A.C.T.) IN PRIMARY CARE CONSULTATIONS

The ACT can be completed and used by any patient with a clinical diagnosis of autism or who self identifies as autistic. This form does NOT have to contain all the information, but it is a basis to help guide the consultation and enable you to convey key information points to healthcare staff. It is important to note that the information listed in this tool is meant to be a summary of the reason for attending the appointment.

The form is:

- To alert healthcare professionals to your neurodiversity so that they know they may need to make reasonable adjustments.
- To help you think about the reason for booking an appointment with the healthcare professional ahead of time which will help you to describe the symptoms within the consultation.
- To provide key information that will alert the healthcare professional of the need to make reasonable adjustments within the consultation.
- To help the healthcare professional ask appropriate questions and ensure that your concerns are discussed.
- The tool does not need to contain all the information you think the healthcare professional needs to know, just enough to guide the interaction.

The communication tool is split up into several sections. You do not need to complete all the sections, just those relevant to you today. Below is a guide that provides information that might be useful to add to each section.

Instructions for Healthcare Staff:

This box is provided to give the healthcare professional information about the purpose of this tool. You do not need to add anything to this box.

Please add a 'reasonable adjustment' flag to my patient records:

This is where you indicate if you would like the healthcare professional to add autism as a 'reasonable adjustments' flag on your electronic medical notes. If this has already been processed through a previous request – tick N/A on the form. For more information on possible adjustments, visit the NHS webpage [Reasonable Adjustment Flag - NHS England Digital](#)

Communication needs:

In this space you would provide the healthcare professional with brief information that might help them to communicate in a way that works for you during your consultation. It might include details of your communication style. A few examples of what you may include are listed below:

- I may sometimes take time to answer questions.' You may let the healthcare professional know this so that they provide you with adequate time to respond to their question, and do not ask another until you have been able to respond.
- I recognise that the way that I express pain is not 'typical', and I report my symptoms in a 'matter of fact' way – but that this is not a reflection of how the pain impacts me'. It is useful for healthcare professionals to know this.
- I prefer straightforward communication to minimise my anxiety. e.g. say "depression" rather than "a bit down/low mood" or "diarrhoea" rather than "upset tummy."
- I may not be very expressive or use gestures. Please do not consider my body language when listening to my answers.
- I may be uncomfortable making eye contact.
- I may monologue about the situation, and it is okay to interrupt me.
- I may react differently to neurotypical patients, i.e., I might laugh or say something out of place.
- I may need to use a fidget gadget to help me concentrate and reduce anxiety.
- Please use precise communication and avoid the use of metaphors, allusions, etc.

Issue to be discussed in consultation:

This should be brief so that the healthcare professional can very easily see what will be discussed in the consultation. You might like to state the problem(s) here that you would like to discuss at the appointment, for example:

- Suicidal thoughts
- Addiction
- Hot flushes
- Low mood
- Mood swings
- Negative thoughts
- Bulimia/disordered eating
- Obsessive behaviour
- Sleep problems
- Forgetfulness
- Weight gain/loss

Further details:

Here, you would provide more information about the issue that you have booked the appointment about. This section is designed to help you think about the way that the issue is affecting you and to help you prepare to answer questions about it within your consultation. The information you provide here will help guide the healthcare professional to ask appropriate questions if they need further details.

Use bullet points or brief notes

If you are attending the consultation for a physical symptom, you might like to include some of the details below to help you describe your symptom:

Site

Where on the body the symptom is located.

It might be useful to mark on the body outline in box 7 where the symptom is.

Onset

How long ago did you start to feel the symptoms?

E.g. Since last week/for two months/for the last three days.

Character

You might like to include details of how the symptom feels. For example, is it a constant symptom? Does it come and go, or does the way it feels change?

Radiation

Does the symptom ever spread beyond the main area?

E.g. usually in your ankle but sometimes spreads to your knee/starts in the right breast but can be felt in the right armpit/ your hip but sometimes spreads to the back.

Associated symptoms

Are you aware of other symptoms that you think might be linked to the main symptom?

If yes, what are these symptoms?

E.g. Difficulty urinating and noticing back ache.

Blood in bowel movement and getting stomach pain.

Swollen knee and recently had a high temperature.

Timing

When do you get the symptoms?

Has the symptom changed over time?

Does the symptom come on during certain activities?

Exacerbating and relieving factors

Does anything make the symptoms worse or better?

E.g. Worse if I use that hand/touch the joint/walk on it, etc.

Painkillers are not working/paracetamol helps a bit/a heat pad is the only thing that works.

Severity

How severe is the symptom?

Healthcare professionals often use a scale of 1–10 to grade things like pain. You might want to use one of the pain scales provided and see if this helps you to describe the severity of the symptom that you are experiencing.

Pain threshold/expression of pain

Pain is individual to everyone and therefore it is important for you to use your own experiences to assess your pain relative to what you have experienced in the past. If you are very tolerant of pain, please let the healthcare professional know.

Remember, the healthcare professional will use this information to gain more clarity on your symptoms—it does not need to be comprehensive and cover everything unless you feel you may be unable to provide more verbal information.

See also the Pain Scale at the end of this document.

A diagram of the body:

This diagram is provided to mark the site of your body where you are experiencing the symptom, should it be helpful. You may also use this diagram to indicate areas of sensitivity for healthcare staff to be aware of for physical examinations

Factors to consider during physical examinations:

During the consultation, if you are attending for a physical symptom, it may be necessary for you to have a physical examination. You may wish to let the healthcare professional know about any concerns you have about physical examinations, such as:

- 'I will/will not want a chaperone if I am having an examination'.
- 'Please tell me what you are going to do before you do it'.
- 'Please use direct communication'.
- 'If you need to touch me, please tell me beforehand and use firm/light pressure'.
- Do you have any specific needs that may be relevant for the healthcare professional to know? E.g. 'I do not like to stand on the ground barefoot. If you need to look at my bare feet, please can I sit on the bed?'
- 'I have sensory issues with latex/paper/nylon/things that rustle'.
- If you need an examination, please provide clear instructions about what to do- e.g. not "pop your things off" but rather a direct instruction like "take off your clothes below your waist."

Other relevant conditions to note:

In this section, you may like to note any other conditions that you want the healthcare professional to know about. This could include:

- Conditions that you feel may be related to autism, such as symptomatic hypermobility, migraine, POTS, Ehlers–Danlos syndrome, epilepsy, and bowel problems.
- Medications that you are on, and if you may be concerned about interactions with any new medication prescribed during your consultation.
- If you have a low or high tolerance for a particular medication.

Information for Care Navigators/Reception Staff:

Think about what you feel is important for non-clinical staff to know.

It is important to consider the setting that you are visiting and what the physical environment is like. Please be aware that it may not be possible to accommodate all your requests.

The form provides a couple of options to tick if you would like to request these reasonable adjustments from non-clinical staff. There is space on the form to add your own suggestions that are appropriate for you and the setting that you are visiting.

Pain Scale

10	Unable to move	I am in bed and cannot move due to my pain. I need someone to take me to the hospital to help me deal with the pain.
9	Severe	My pain is all I can think about. I can barely move or talk because of the pain.
8	Intense	My pain is so severe that it is hard to think of anything else. Talking and listening is difficult.
7	Unmanageable	I am in pain most of the time. It prevents me from doing most of my normal activities.
6	Distressing	I think about my pain all the time. I give up many of my normal activities because of pain.
5	Distracting	I think about my pain most of the time. I cannot do some of the normal activities I need to do each day because of the pain.
4	Moderate	I am constantly aware of my pain, but I can do most of my normal daily activities.
3	Uncomfortable	My pain bothers me, but I can ignore it most of the time.
2	Mild	I have a low level of pain. I am only aware of it when I pay attention to it.
1	Minimal	My pain is hardly noticeable.
0	No Pain	I have no pain.