

SERVIZIO SANITARIO REGIONALE EMILIA-ROMAGNA Azienda Unità Sanitaria Locale di Reggio Emilia IRCCS Istituto in tenologia avanzate e modelli assistenziali in oncologia

ACHIEVING BOWEL AND BLADDER CONTROL

RAGGIUNGERE IL CONTROLLO SFINTERICO

Advice and guidance for family members of children with neurodevelopmental disorders, in particular autism spectrum disorders



This guide was produced for the research thesis of Ilaria Lalinga, *final*year student in Psychiatric Rehabilitation Technology at the University of Modena and Reggio Emilia, and follows on from the project of Viani Federica, Psychiatric Rehabilitation Technician at the Reggio Emilia Autism Centre, prepared under the supervision of Dr. Virginia Giuberti, Psychologist and Psychotherapist, Director of the Reggio Emilia Autism Centre, and with the collaboration of Dr. Gino Montagna and Dr. Francesca Bontempo, Paediatricians at the Reggio Emilia Local Health Authority.

The images in this guide and in the attached online files were taken from the Aragon Augmentative and Alternative Communication (AAC) Portal *https:\\www.arasaac.org* Pictograms by: Sergio Palao Source: *ARASAAC (http://arasaac.org)* Licences: CC (BY-NC-SA) Ownership: Government of Aragon

INTRODUCTION

Here at the Autism Centre, we are often asked to provide information and answers to the many questions and doubts that parents have about achieving bladder and bowel control in their children (ability to use the toilet).

This guide was created to provide help and support in relation to bladder and bowel control through a series of techniques and suggestions.





But remember, besides the strategies and techniques, every child is different, and one method that works for one may not work for another. Similar "*toilet training*" or "*potty training*" techniques can be found in the scientific literature, but with some differences.

It is very important to create an **individual approach** for your child and we recommend discussing this with your child's specialist team before starting (neuropsychiatrist or psychologist, therapists, paediatricians) as well as with your child's teachers, who can observe their routine and dayto-day life at pre-school.

Independence is not an innate ability, but is acquired gradually through **teaching and help from adults**, so we need **patience and determination**. Bladder and bowel control is acquired roughly between 18 months and 3 years, but this **varies from child to child**: some children learn earlier, others take longer.

Additional material can be consulted, downloaded and printed from the Reggio Emilia Local Health Authority website at the following link: https://www.ausl.re.it/programma-autismo-e-disturbi-dello-spettro-autistico-asd-

• Annex 1. Full version of this guide

(a comprehensive guide with more detailed guidance)

- Annex 2. Bowel movement and urination pattern table
- Annex 3. Images (for toilet transition, visual sequences, rewards, etc.)
- Annex 4. Bibliography
- Annex 5. Illustrated children's books on the topic

PRACTICAL ADVICE

A gradual approach is recommended

We advise you start adopting "toilet training" strategies in the **spring** for "damage limitation" purposes: any "accidents" that may happen will be easier to deal with than in winter (e.g. less clothing gets wet or dirty and it washes and dries faster), and you'll have more time available to teach and try things out (spring and summer).



To start off, we'll work only on **daytime bladder and bowel control** (*the times when your child is awake*), and only afterwards will we deal with **night-time control**, when your child is sleeping (*afternoon nap and night-time*).

Our initial goal will only be to teach the ability to poo and pee in the toilet. The adult may have to do all the remaining steps for the child.

Remember that the ability to go to the toilet completely independently is made up of many different skills (*e.g. recognising the need to go to the toilet, communicating that need, waiting before pooing/peeing, going into the bathroom, pulling down trousers, etc.*). For example, whether the child communicates the need to go to the toilet is a goal we can pursue later on. In fact, at the start of the process, it is you as parents that should suggest going to the toilet to your child at set times. Only later will they express the need and ask you to take them to the toilet.

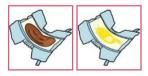


We will now take a brief look at the **steps** you can take to teach your child bladder and bowel control and independence when going to the toilet.

The suggestions can then be adapted to your child.

Step One | ASSESSING YOUR CHILD'S NATURAL RHYTHMS

First of all, it is important to identify your child's **bowel movement** and urination pattern, i.e. to try to understand whether they have more or less regular natural rhythms, identifying the times when they are most likely to pee or poo.



Keep using nappies for the first two weeks (can be replaced by pull-ups, which are much more practical) and take your child to the bathroom roughly once an hour to check if it is wet, dirty or clean. You may find it easier to record the information in the **table** you can print out from the Autism Centre website.

We also suggest **sitting your child on the toilet for a few minutes**, without forcing them, changing their nappy only if it is wet or dirty.

This step can sometimes last more than two weeks and should be assessed based on the needs of the child and the family.

Step Two | ESTABLISHING WHEN TO GO TO THE TOILET

Following this two-week period, look at the table and:

- 1. Assess if your child is ready to continue with the toilet training, considering the following requirements:
 - They are dry for periods of at least one and a half hours.
 - **They show** some signs of knowing they are wet or dirty or they come to a stop while peeing or pooing.
 - They accept being accompanied to the toilet.
 - **They accept staying** seated on the toilet for at least 5 minutes, starting from 1 minute and gradually increasing the time.

The time needed to reach these requirements may be longer than two weeks. To help your child, you can find advice and guidance in the full version of the guide on the Autism Centre website.

2. Determining which skill to start with: do we teach urination or bowel movements first?

The decision to start toilet training with peeing or pooing first is up to you and varies from child to child.

However, you should consider that peeing is more frequent and less predictable than pooing.

Therefore, if your child poos regularly, you should take advantage of this and teach them by starting to put them on the toilet at times when they usually have a bowel movement because there is a higher likelihood of success with less effort. This is because:

- it occurs less frequently and more systematically than peeing;
- **it is easier** to understand the signs (*e.g. the child strains, squats, turns red...*);
- the child is more likely to have a bowel movement each time they go to the toilet.

Once the child has learned to poo on the toilet rather than in a nappy, it will be easier to move onto peeing because the child will already be more familiar with going to the toilet.

If, on the other hand, your child has no regular routines, assess where to start based on their habits (e.g. if pooing is stressful for them, or if they have specific and established habits and you would risk upsetting them, it is better not to start with this).

3. Establishing when to go to the toilet.

The information you collected the two weeks before starting *"toilet training"* will help you to establish the times when your child is most likely to have a natural need to go to the toilet as well as their continence interval, i.e. the length of time between pees.



Based on this information, you can set rough times at which to take them to the toilet, trying to predict their natural routine to prevent accidents.

In the tables, the times with the highest number of *poos* or *pees* over the two-week period correspond to the bowel movement and urination pattern of your child.

- Bowel movements:
 - ✓ *if your child's pattern is regular*: you should take them to the toilet 15 minutes before the time they generally have a bowel movement;
 - ✓ if your child does not have a regular pattern: you should take them to the toilet 15 minutes before the first time you marked poo in nappy on the chart, then keep trying every 2 hours until they poo.
- Urination:

the times at which your child urinates will be more frequent, so you should choose between 4 and 8 times a day in which there is a higher likelihood that they will pee based on the table, or you can choose regular times based on their continence interval (*e.g. if your child pees every two hours, take them to the toilet regularly a short time before the two hours are up*).

Step Three | PREPARING THE ENVIRONMENT

Before you start taking your child to the toilet according to your planned schedule, it is recommended that you prepare the environment and



routine to increase your chances of success.

• **Be consistent and predictable**: at the start, you need to follow the toilet routine every day, without too many changes.



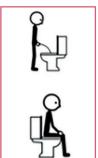
• **Get everyone involved**: tell everyone involved in the life of your child (*grandparents, other relatives, teachers, carers etc.*) about the method you're using and give them a change of clothes just in case of any "accidents".

- **Do everything in the bathroom** (e.g. nappy chanae, sitting on the toilet, chanaing soiled clothing, etc.). This will help your child to associate this behaviour with a particular location (the bathroom).
- Reduce distractions: we recommend removing any sources of distraction from the bathroom toys and objects that might be appealing or distracting from the task in hand (*if you have more* than one bathroom at home, decide which one to use, choosing the most "uncluttered" one, i.e. the one with the fewest objects associated with other activities).
- **Use the normal toilet** right from the start. placing a seat reducer on top to make it more comfortable and stable to sit on. Choose a colourful and eve-catching reducer, possibly with vour child's favourite characters. You can use a step to help your child climb up and to rest their feet on (this is practical because the position with the feet supported and the leas bent at 90° at knee height makes it easier to push out the stool). If you'd prefer to use a potty, keep it in the bathroom and always use it there.
- If you have a boy, decide if you want to teach him to pee standing up or sitting **down**: at the beginning it is better from the seated position for two reasons - you avoid the step of having to "support" the penis, and when sitting, it is also possible to pick up on any urge to poo. Whichever way you decide to do it, the important thing is that all the adults who care for your child are aware of this and do the same thing.
- **Give your child plenty to drink** (*water or other* suitable drinks): encouraging fluid intake promotes both urination and bowel movements; it is useful in general, but especially with children who "hold back" when using the toilet.







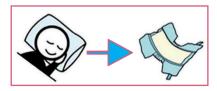


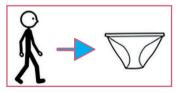




 Be consistent when replacing nappies with normal pants: it is best not to confuse the child by putting on and taking off their nappy over the course of a day and according to the situation or needs.

The clearest message you can give your child is to *associate nappies* with going to bed and pants with being awake.





To make car journeys easier, you can use disposable liners for the car seat; when leaving the house, always take multiple changes of clothing and when you reach your destination, find out where the toilet is and take your child at regular intervals to keep up the training.

 Introduce your child to the toilet routine in an "indirect" way: during playtime, you can tell funny stories where their favourite toy, doll or character does many things, including going to the toilet.





Or you can read children's picture books, watch videos or cartoons together, or specially created stories dealing with the specific topic of going to the toilet.

Use a transition object or a visual aid (*picture*): it may be helpful to give your child a transition object associated with going to the toilet or a photograph of a toilet to take to the bathroom. This helps the child understand where they are going and what will happen there. Later, if your child is not yet able to speak, the picture can be used by the child to communicate to the adult the need to go to the toilet.

 Prepare visual aids and establish a routine with the help of pictures: it is recommended that you place a sequence of images in the bathroom (*photographs or pictures*) about the toilet routine - this helps communicate all the useful information

to the child (also overcoming any potential difficulties of understanding explanations through verbal language alone) and it lets the child know

and be clear about what is about to happen and what the steps are. At the end of the sequence of images, you can also add a picture of the reward the child will receive.

- Learn to recognise the signs your child gives: it is useful to recognise the signs that each child gives, even unintentionally, before peeing or pooing (e.g. becomes red in the face, bends over, goes quiet, goes into a corner, etc.) and as soon as you see this, take the child to the toilet even if the time is outside the schedule you've prepared.
- Give rewards: use small rewards, together with praise and compliments, above all in the early stages. This will make your child more motivated to use the toilet and will make learning faster and more enjoyable. Later on, once the child has learned what to do, gradually reduce them and eventually stop them, as they will no longer be needed.

The reward must be *something your child really wants*, but is used *exclusively in the toilet to reward the child's effort* during the training period.

Make sure the rewards can't be reached by the child any other time of day or in other places.

Decide whether to use a small snack (*e.g. crisps, sweets, etc.*), which have the advantage of being consumed quickly and therefore will not be distracting. Alternatively use an activity or toy that your child enjoys.







Step Four | CREATING A TOILET ROUTINE

Now it's time to start the real toilet training, accompanying your child to the bathroom at regular times, replacing nappies with pants (*during the day*) and creating a toilet routine.

• **Take your child to the toilet** at the scheduled times or when they give signs of needing to go. Pull down your child's trousers to below the knee (*if they manage to do this themselves, even part of the way, you should encourage them to do so*) and get them to sit on the toilet.



Get them to **sit there for at least 5 minutes**, waiting with them.

Praise them every so often for remaining seated. (e.g. "That's great! You're sitting on the toilet all by yourself!") and explain what they should do in a direct way which is not demanding or an order.

- If they pee or poo, praise them cheerfully and immediately give them their reward. Immediately afterwards clean them and leave the bathroom.
- If they haven't peed or pooed after 5 minutes, get them down from the toilet and leave the bathroom until the next scheduled time or until they show signs of needing to go to the toilet.
- If your child has an "accident", i.e. they poo or pee in their pants, don't tell them off but rather take them to the bathroom and remove their soiled clothes. Point to the toilet and remind them to "poo/pee in the toilet". Also, in the case of a poo, it could be useful to "empty" their soiled pants into the toilet.

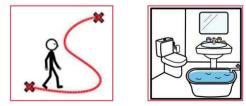
To start with this can be quite inconvenient for the adult because there could be a lot of "*accidents*", but this is a normal and necessary step as your child was used to going to the toilet in their nappy.

It is very important not to shout and make the child feel bad if they don't manage to use the toilet at the start.

Step Five | TEACHING YOUR CHILD TO BE COMPLETELY INDEPENDENT IN THE BATHROOM

When your child has eventually learned to hold on before pooing or peeing and to use the bathroom, you can then teach them the other skills they need to be completely independent in the whole series of actions that make up going to the toilet (*ability to go to the toilet independently*) including, for example, **taking down and pulling up their trousers and pants, correctly using toilet paper, flushing the toilet, being in the bathroom on their own**, and **going to the bathroom alone when told to by an adult**.

It is important to pay particular attention to the **ability to communicate the need to go to the toilet**, both if your child can use verbal language or if they can't. In this case, you will have to teach the child to use the augmentative and alternative communication (AAC) tool that the child already knows (*pictures or signs*). You can consult our website for further information on learning these skills. The end goal is always to **encourage your child's complete independence by gradually reducing adult prompting or help.**

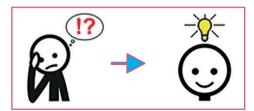


However, your child may well have learned these individual steps without being able to carry them out without a little help from an adult, or without constant prompting, or without being able to complete them in sequence.

 What to do if your child "forgets or skips" one of the steps in the sequence: if you see that they need help, you can physically help them (or stand close-by and guide them to the next step), or show them the step on the sequence of images, or, if the child can talk and is able to respond, try asking: "what do you need to do?" rather than suggesting it directly.

TIPS ON HOW TO OVERCOME SPECIFIC PROBLEMS

When teaching your child how to use the toilet, you may come across some problems at certain stages. In this case, it is very important first of all to try and imagine things from your child's point of view: *why won't they do the specific thing you're asking them to do? Why are they not responding in the way you expect?*



Once we have imagined or understood the "why", we can think about how to overcome the problem, helping the child with strategies or simplifying/clarifying the task with visual aids to increase understanding, cooperation and motivation.

The Local Health Authority website contains strategies and advice that you may find useful with the **following difficulties**, if your child:

- Refuses to sit on the toilet.
- Doesn't sit on the toilet for long enough.
- Holds back when their nappy is removed or doesn't understand how to release urine.
- Doesn't produce anything every time they are on the toilet.
- Has a lot of "accidents" when they soil themselves outside the schedule you have created for going to the toilet.
- Is frightened of flushing the toilet.
- Has an excessive interest in flushing the toilet which distracts them from sitting on the toilet.
- Plays with the toilet paper.
- Doesn't want to be cleaned.
- Doesn't want to wear pants and wants their nappy.

PAEDIATRICIANS' ANSWERS TO YOUR QUESTIONS AND CONCERNS

It is normal for parents to be overwhelmed by doubts and questions when teaching their child to use the toilet correctly.

Paediatricians at the Reggio Emilia Local Health Authority have been involved in preparing this guide to give you comprehensive and detailed answers and information based on medical findings.





You'll find answers given by paediatricians to the most frequently asked questions on the Local Health Authority website:

- How is peeing regulated naturally?
- How often should my child pee? Sometimes they don't go for hours!
- Sometimes they hold their pee for a long time, even for hours or a whole day! I'm afraid that if they hold their urine for too long their bladder will burst or there will be serious damage! Or they'll get dehydrated!
- I'm afraid that if they hold their poo for too long there will be serious damage!
- During the two-week assessment period their nappy was always wet... what does this mean?

We would like to remind you that this information is of a general nature. If you would like to know more in relation to your child, we recommend you consult your paediatrician.

On the Local Health Authority website, at the link below, you can consult, download and print:

- the full version of the **guide**, with more information and more detailed instructions;
- the files with the materials referenced in this guide (tables, pictures for transitions to the bathroom, visual sequences, recommended books, etc.)

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