

## Consent

- Ensuring informed consent with someone who has a language disorder can be difficult. Working with a Speech and Language Therapist and a caregiver and using easy read information can be extremely helpful.
- The person with Down syndrome has the right to understand what is being proposed, and the consequences of treatment (or no treatment). Taking time and space to ensure that information is clearly communicated and understood is essential.
- The HSE's National Consent Policy 2017 outlines the duty on health and social care professionals to maximise capacity through supported decision-making.



## References

11-2001-American-Family-Physician-Guidelines-For-Adults-with-DS.pdf

<https://booksbeyondwords.co.uk>

FCIC\_PhysicianFactSheet\_1\_Improving\_Communication.pdf

<https://www.hse.ie/eng/about/who/qid/other-quality-improvement-programmes/consent/national%20consent%20policymay14.pdf>

<https://www.mencap.org.uk/get-involved/campaign-mencap/current-campaigns/treat-me-well/treat-me-well-resources-hospital>



**Down Syndrome Ireland**

Ph: 01 4266500

E: [info@downsyndrome.ie](mailto:info@downsyndrome.ie)

[www.downsyndrome.ie](http://www.downsyndrome.ie)



# How

Healthcare Professionals  
can improve the hospital  
experience for adults with  
Down syndrome



## General Points

- Hospitals are noisy and unpredictable, which can be particularly challenging for some adults with Down syndrome, especially those with hearing loss.
- Some degree of language disorder is universal in people with Down syndrome, often causing difficulties processing spoken instructions and information.
- Feeling unwell, disorientated and insecure makes it even more difficult to process information.
- Use of resources such as 'Books Beyond Words' help prepare people for forthcoming appointments, procedures, etc.
- Be conscious of the risk of 'diagnostic overshadowing'. Symptoms can be mistakenly attributed to the patient's disability rather than their current ill health.
- Provide patients with appropriate materials to take home i.e. adapted literature that uses visual aids and is in an easy read format.

## Communication

- Ask questions in a quiet environment.
- Use age appropriate language and tone.

- Begin your interview by identifying yourself, explaining the purpose of the appointment and finding out about communication preferences.
- Explain why you are asking questions, using equipment, etc. Let the person know what you are going to do before you do it.
- Always speak to the patient first. Use their caregiver to help facilitate communication, not as a substitute for communication.

### Use short sentences and count to 10 after talking to allow the person time to think and respond.

- Use pictures and written words to support understanding.
- Be aware that abstract language and questions about time will be particularly difficult for some people to understand.
- Open questions will usually give you more information than closed questions ("what happened?" is better than "did you fall over?").
- When given a choice, many people will echo the last option you suggest. To find out what the person really wants, use written words or pictures and give them time to choose.

- Find out the individual's baseline in terms of alertness, responsiveness, tone, etc. by asking them or a family member in order to make a correct assessment.



### Suggestions from adults who have Down syndrome - How to make our visit to hospital better:

- More beds.
- More bathrooms.
- Bedside manners - Doctors and nurses ask me appropriate questions.
- Check are you ok? Ask questions - What is your name? Where are you from? What is your age?
- Don't talk only to my parents - talk to me too!
- Ask me - Can you touch me?
- Make the place comfortable, i.e. cushions.