

Access to special care dentistry, part 2. Communication

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IN BRIEF

- Good communication helps to reduce patient anxiety whilst enhancing patient satisfaction and minimising misunderstandings and complaints.
- A number of disabilities can impact on 'normal' communication practice.
- Where communication cannot be met through speech, non-verbal methods should be considered.
- It is important not to pretend to understand speech which is not clear.

This article considers what communication is, its elements, what helps and what hinders it, and why it matters. It also considers managing people with communication differences and when communication is affected in special care dentistry (SCD). The article focuses on patients with hearing and visual impairments and considers how communication is affected and what techniques can be used to improve the situation. It offers recommendations for communicating with patients with neurological impairments typically seen after stroke, such as aphasia and dysarthria, with tips for the listener including the use of communication aids where appropriate. Finally it will consider communicating with patients who have autistic spectrum conditions and discuss how effective techniques and a tailored approach to their specific needs and anxieties can increase the likelihood of a successful dental visit.

The first part of this article considers what communication is, its elements, what helps and what hinders it, and why communication matters. The second part looks at managing people with

communication differences and when communication is affected in special care dentistry (SCD). It will take a number of different types of disability, consider how communication is affected, and what techniques or alternative and augmentative communication devices can be used to improve the situation.

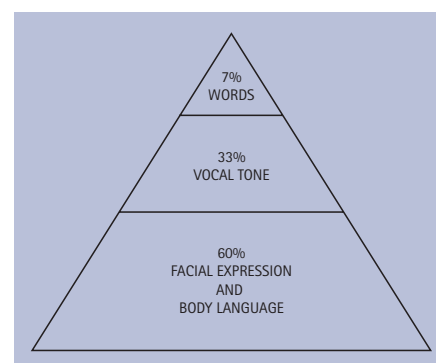


Fig. 1 'The communication triangle' denoting the percentage value of elements of communications. Source: reference 1

ACCESS TO SPECIAL CARE DENTISTRY

1. Access
2. Communication
3. Consent
4. Education
5. Safety
6. Special care dentistry services for adolescents and young adults
7. Special care dentistry services for middle-aged people. Part 1
8. Special care dentistry services for middle-aged people. Part 2
9. Special care dentistry services for older people

PART A – COMMUNICATION

What is communication?

Communication is a complex system of sending, receiving and interpreting messages. At its simplest it is a two way process, involving a sender and a receiver. Communication can be described as: *'a shared system of signals which requires systematic encoding and appropriate decoding of signals'*. Skilled communication entails that the signal sent and the signal received are the same, regardless of the system of signals used, eg language, symbols or pictures.

The importance of communication

Good communication is fundamental to good clinical practice. It is important as it allows us to inform, be informed and to exchange information – all important to understanding the patient's reason for attendance, their medical history, to explain treatment needs and gain informed con-

sent, and to provide appropriate preventive advice. Good communication makes life easier by facilitating the building of patient rapport and trust, thus helping to reduce patient anxiety whilst enhancing patient satisfaction and compliance. All of this contributes to a better patient experience and an improved experience for the dental team, as well as minimising misunderstandings and complaints.¹

The elements of communication

There are three main elements of communication: words, tone of voice and body language. Whilst effort is put into selecting the 'right' words to use, on their own they account for only a small part of communication (Fig. 1). Even so,

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they are used to transmit what we want to say. The message needs to be clear and jargon-free and take account of the fact that the same words can mean different things to different people. Reflecting and checking out understanding is a useful way of monitoring comprehension.

Whilst words or verbal communication (VC) only account for 7% of transmission, tone of voice is estimated to convey 33% and body language or non-verbal communication (NVC) 60% of the message. If VC and NVC are not congruent, it is the non-verbal elements (such as facial expression, body posture and gestures) that will be believed. Sending 'mixed messages' can lead to misunderstandings.

Receiving information involves active listening to all the elements of communication, plus non-verbal and verbal feedback. Attentive listening is indicated by facing the speaker at the same level, leaning forward slightly to signal interest, making appropriate eye contact, making encouraging sounds or gestures to continue, and reflecting on what has been said (Fig. 2). Receiving mixed messages from patients can help you to pick up on their 'real' feelings, for example the patient who says they are fine but whose body language is telling you they are uncomfortable and anxious in the dental setting. A comment such as 'You seem a little on edge this morning?' can enable them to verbalise the real message. Wanless provides the useful acronym SOLER – square, open, leaning, eye contact, and relaxed – as an *aide memoir* for demonstrating attentive listening.²

Additionally, reinforcement of messages and a brief summary of the main points help people to remember salient information.²

PART B – MANAGING PEOPLE WITH COMMUNICATION DIFFERENCES

Effective communication is not easy. It is a complicated process that, like any skill, can be learned and improved. A number of parameters and disabilities can impact on 'normal' communication processes. This section seeks to explore how communication can be enhanced in some of those conditions.



Fig. 2 British sign language being 'spoken'

Table 1 Degrees of deafness

Degree of deafness	Quietest sounds heard, in decibels	Possible impact
Mild	25-39	Difficulty following speech in noisy situations
Moderate	40-69	Difficulty following speech without a hearing aid
Severe	70-94	Reliant on lip-reading even with a hearing aid. Sign language may be preferred mode of communication
Profound	>95	Sign language may be preferred mode of communication

Anxiety and communication

A large proportion of the general population reports feeling anxious in the dental setting.³ Anxiety can impact on the complex process of communication, making it more difficult to hear, retain and comprehend information. Wherever possible, it is prudent to give explanations away from the dental setting, provide written back-up material that can be taken away and read at home, and allow time for questions after a period of reflection. For people with profound dental anxiety, it may necessitate meeting them away from the dental environment for the assessment visit. Domiciliary visits can be used to good effect in this situation.

Sensory disability

Communication relies, to a large extent, on seeing and hearing. If one or other of these sensory systems is impaired, the communication process can also be impaired. This can have a profound

effect on access to dental services by complicating the appointment making process. In the dental setting the ability to ascertain vital information during history taking, to build patient rapport and to provide effective preventive information can be prejudiced. The communication process can become time-consuming and frustrating for all involved if it is not well managed.⁴

Hearing impairment

What little information there is in the dental literature regarding the effect of hearing loss on oral health relates to the effects of conditions such as Behçet's disease⁵ and cleft palate⁶ on hearing. The best resources for tips on communicating with deaf people are available on the Royal National Institute for Deaf People⁷ and the Royal Association for Deaf People⁸ websites.

Deaf is a general term used to refer to people with all degrees of hearing loss, with the level of deafness defined by the

quietest sound a person can hear (Table 1). Hearing impairment or deafness can be congenital, inherited, or acquired throughout life as the result of accident, disease, or as part of the ageing process. It affects approximately 9 million people (one in seven of the UK population), with most of them having developed a hearing loss with age. Around 2% of young adults are affected by hearing impairment, whereas it is estimated that this rises to 55% for people aged 60 years and over.

Additionally, it is estimated that one in five people experiences some degree of tinnitus – ‘a sensation of ringing in the ears, or other head noises, perceived in the absence of any external noise source.’⁷ Noises may occur unilaterally or bilaterally, be intermittent or continuous, and vary in pitch from a low roaring to a high squealing or whining. It is often associated with deafness but can cause trouble with hearing even when there is no associated deafness.

It can be difficult to recognise deafness, often referred to as the ‘invisible disability’, as there may be no visual clues that the person has a severe hearing loss and profoundly deaf people may not wear hearing aids. Some deaf people carry, and will present you with, a Hearing Concern Sympathetic Hearing card. You can assume that the bearer has a hearing loss and may have difficulty communicating.⁸ Sign language users who are deaf-without-speech are often prepared with pen and paper and may present you with a pre-typed or hand-written note. Speech may also give a clue, as it can sound a little strange as the individual cannot hear their own voice and may have learned to speak never having heard a single word.⁸

If you recognise a person as deaf, ask them what their preferred method of communication is, record it in the notes and ensure it is used. The way in which deaf people communicate often depends on the time in their lives when they lost their hearing. Those who were born deaf, or lost their hearing before learning to speak, will generally be sign language users. People who have lost their hearing in later life, after they have learnt to speak, will generally communicate by lip-reading and speech. Do not assume that a person wearing hearing aids can

hear what you are saying, as they may only be able to hear particular sounds or background noise.

Deafness would appear not to affect the dental attendance of children, presumably because they have someone to make the appointments for them. However, around two thirds of them experience difficulties in communication at the dental visit, including being called from the waiting room, communicating with the dentist and/or nurse and understanding what will take place in the dental visit.⁴ Communicating with someone who is deaf or hard of hearing is not difficult. There are a number of basic rules you can follow to enable successful communication (Table 2), and there is a range of communication support available which can help.

People with hearing impairment may rely on:

Hearing aids – always ensure that the device is switched on for communication. They are often turned off before entry to the dental surgery, in expectation of the high-pitched whistling interference that may occur when in close proximity to the dentist and some dental equipment. You may need to ask the individual to switch the aid back on for periods of communication.

Lip-reading – by following the general communication guidance in Table 2

and speaking clearly in a normal cadence and tone, it is usually possible for people to lip read.

Language service providers (LSP) – includes ‘lipspeakers’ and ‘British Sign Language (BSL) speakers’. Lipspeakers repeat what is said without using their voice, so that lips can be read easily. They use natural gestures and facial expressions to help the person follow what is being said, and will also use finger-spelling if asked. BSL uses manual and non-manual components such as hand shapes and movements, facial expression and shoulder movement (Fig. 2). Unless someone in the practice can sign, an interpreter will be needed. Your local communication services office should be able to help. If possible, meeting the interpreter in advance of the appointment to discuss dental terminology and interpretation needs is useful.

Other technical aids – there are a number available that can help overcome hearing impairments and improve access to dental care, for example minicom (Fig. 3), text machines and induction hearing loops. There are an estimated 450,000 deaf, hard of hearing, speech-impaired and deafblind people in the UK who cannot use a standard telephone. For them, textphone communications provide a vital lifeline, along with Text-Direct and Typetalk.

Table 2 Hearing impairment – tips for improving communication

- Position yourself with your face to the light so you can be seen clearly and face the patient so they can read your lips. Remove your facemask or wear a clear face shield to facilitate lip reading
- If you are using communication support always remember to talk directly to the person you are communicating with, not the interpreter
- Minimise background noise (such as music), distractions and interruptions
- Allow extra time for the person to respond
- If what you say is not understood, do not keep repeating it. Try saying it in a different way instead
- Speak clearly but not too slowly, do not exaggerate your lip movements, and use natural facial expressions and gestures
- Avoid jargon and unfamiliar abbreviations
- Resist the urge to shout – it will not help, is uncomfortable for a hearing aid user and looks aggressive
- Lower the pitch of your voice – it is more effective than raising the pitch as people lose high pitch hearing first
- Use gestures for visual feedback, such as a thumbs up for ‘you are doing well’
- Be prepared to write down what you have to say or have pre-prepared written prompts to save time
- Check that the person you are talking to can follow you. Be patient and take the time to communicate properly
- Make appointments and communicate with the patient through texting



Fig. 3 Minicom machine used for communication by people with a hearing impairment

Hearing dogs – only totally or profoundly deaf people are likely to have a hearing dog. It is trained to alert them to everyday sounds such as an alarm clock, doorbell, telephone, smoke alarm etc. The dogs communicate by touch and then lead the individual to the sound source, providing a deaf person with greater independence and confidence.

Visual impairment

Visual impairment refers to a visual disability that cannot be corrected by spectacles, and includes people entitled to register as blind or partially sighted, who have difficulty reading an ordinary-print newspaper, or whose sight restricts their mobility. The term 'partial sightedness' refers to people who cannot see clearly how many fingers are being held up at a distance of six metres or less (even with their glasses or lenses), and blindness refers to an inability to see clearly how many fingers are being held up at a distance of three metres or less (even with their glasses or lenses).⁹

There are an estimated 1.7 million people over the age of 65 with sight problems in the UK, representing 90% of all visually impaired people. Most of them have lost their sight gradually and many have an additional disability or illness. Most visually impaired people, even those registered blind, have some residual sight and only 4% can-

not distinguish between light and dark. Around 400,000 people are registered as blind or partially sighted. The symptoms of sight loss depend greatly on the cause and can be due to disease, nerve damage or accidents. Common causes of visual impairment are set out in Table 3.

People with a visual impairment may be recognisable because they wear specialised glasses (Fig. 4), carry a white stick and/or are accompanied by a guide dog (Fig. 5). It is important to ascertain how much residual vision they have and their preferred method of communication.

General principles can aid communication and comfort in the dental setting, for example tactile feedback, such as a handshake on meeting, guiding the person through the practice by allowing them to take hold of your elbow rather than taking them by the arm, and warning them if you are coming to any steps and saying how many. If they have a guide or assistance dog, check out if the dog will remain in the waiting room or accompany them into the surgery. Dogs of this nature are well trained and behaved and are not startled by loud or sudden noises such as the air-rotor or high volume aspirator.⁹ When speaking to the individual, face them and ensure that there is no strong back lighting as this interferes with residual vision. Keep them informed of each step in the procedure, especially when there is about to



Fig. 4 Individual recognisable as having a visual impairment through wearing of specialised glasses

be a sudden noise or sensation, and try to describe procedures in terms of how they will sound, feel, taste and smell.¹⁰

To communicate effectively with visually impaired people you need to consider printed material (including letters, appointment cards and information sheets), signage in the practice and alternative ways of presenting information, such as spoken word, cassette or CD and tactile formats such as Braille. The Royal National Institute of Blind People website provides 'Clear Print' guidelines for written materials and signage.¹¹ As a matter of course, it recommends all written material being on matt paper in font size 14 or more with text in mixed case rather than capitals.

Deafblindness

Deafblind people have a combined sight and hearing loss which leads to difficulties in communication, mobility and accessing information. It has been described as one of the loneliest conditions in the world. Understanding your surroundings without sight or hearing can lead to feelings of isolation and helplessness, depression and difficulties with daily living activities.

It is not a common condition, affecting around 24,000 people in the UK. If the number of older people who are losing both their sight and hearing is taken into account, the number of people

with a combined sight and hearing loss increases tenfold, with some being totally deaf and totally blind and others having some residual hearing and/or vision.¹² It is common for people with congenital deafblindness (eg due to rubella infection) to have other disabilities, such as learning difficulties, epilepsy and severe physical disabilities.

People who are blind and deaf may carry a white and red cane so that their disability can be recognised. A significant proportion of deafblind people still have a little useful sight and hearing, which can be assisted by wearing glasses and hearing aids. Ask the individual, or their carer, what their preferred method of communication is. General principles for communication with hearing impaired and visually impaired people should be used. Remember to approach them gently, tap their arm to let them know you're there and never to walk off leaving the person stranded. Any additional communication support required may depend on when the dual sensory loss was developed. Generally speaking, people born deafblind are likely to communicate through the use of symbols, objects of reference or sign language and will require specialist services to meet their needs. People who have adapted to visual impairment during their lives and are now losing their hearing may need to rely on tactile sign language. Older people with hearing loss (whose usual means of communication relies on lip-reading or sign language) who are now losing their sight may require large print initially, and reach a stage where they too rely on a tactile form of sign language.

DEAFBLIND UK provides an information sheet that provides two simple methods of sign language in visual form for easy learning and/or reference – the 'Block Alphabet' and the 'Deafblind Manual Alphabet'. Deafblind people with a little sight need information provided in large print to be able to read it. Those who are blind require their information in a tactile form such as 'Braille' or 'Moon'. People with residual hearing may prefer to have information provided on audio cassette.

Sensory disabilities are common and the dental team needs to be prepared to communicate with people who

Table 3 Conditions causing visual impairment

Condition	Age group	Predisposition	Impairment	Disability
Macular degeneration	60+ years	Often age-related	Both eyes affected Central vision blurred/distorted Light sensitivity Central blank patch/dark spot	Reading, writing and recognising faces/small objects is difficult Usually retention of sufficient peripheral vision to get around and maintain independence
Cataracts	Any age 50% of 65-74 year olds 70% >75 years	Age Diabetes	Decreased visual acuity Reduced colour contrast Sensitivity to light and glare Double vision	Blurred distance vision Difficulty seeing in poor lighting Difficulty reading
Diabetic retinopathy	Any age Usually middle age onwards	Poorly controlled diabetes	'Floaters' in visual field	Blurred/double vision Difficulty focusing Blindness
Glaucoma	1% >40 years 5% >65 years	Family history African origin	Causes tunnel vision first Eventually causes total loss of field of vision	Able to read small print but not large print Blindness



Fig. 5 Visually impaired person with guide dog being accompanied across the road by a friend

have them. Designing changes to the practice with people with sensory disability in mind ensures that everyone's needs are met.

Neurological deficits

Neurological disease can affect communication in different ways depending on the function of the area of the brain affected by the deficit.¹³ Almost

any acquired brain injury, however slight, may cause memory problems, contributing to language, spatial-perceptual and retention span difficulties. For most stroke survivors, remembering old information (from before the stroke) remains easy, while new learning is difficult.¹⁴ Commonly occurring neurological communication impairments include aphasia and dysarthria.

Aphasia

Aphasia is an acquired communication impairment resulting from damage to portions of the brain responsible for speech. It is a disorder that impairs a person's ability to process language and has a huge negative social, physical and emotional impact on the individual.¹⁵ It is more common than multiple sclerosis, Parkinson's disease or muscular dystrophy, yet several international surveys reveal that there is low awareness of this severely disabling condition.^{16,17}

Aphasia usually occurs suddenly, often as the result of a stroke or head injury, but it can also develop slowly, as in the case of a brain tumour. The most common cause is stroke, where 23-40% of survivors acquire long-term aphasia.¹⁸ The condition does not affect intelligence but it can affect all four modalities of language – reading, writing, comprehension and expression – to varying degrees. Some people with aphasia have problems primarily with expressive language (how they speak), while others have their major problems with receptive language (how they understand). The nature of the problem varies from person to person and depends on many factors, but most importantly on the amount and location of the damage to the brain. Usually reading and writing are more impaired than oral communication.¹⁹

The commonly recognised types of aphasia include:

Global aphasia – the most severe form, where people can produce few recognisable words and can no longer read or write, leaving them very isolated.

Broca's aphasia – where individuals have damage to the frontal lobe of the brain. Whilst there is better understanding of conversation, speech output is severely reduced. The limited vocabulary is restricted to short utterances of less than four words produced with great effort. Small words such as 'is,' 'and' and 'the' are often omitted, leaving speech open to interpretation. For example, a person with Broca's aphasia may say, 'Walk dog', meaning 'I will take the dog for a walk'. However, the same sentence could also mean 'You take the dog for a walk' or 'The dog walked out of the house', depending on the circumstances.²⁰

Table 4 Recommendations for communicating with a person with aphasia

• Avoid being condescending, treat the aphasic person as the mature adult that (s)he is
• Choose a quiet place with few distractions. Background noise and more than one person speaking at once can make it hard to follow a conversation
• Ensure eye contact before starting to speak, so that facial expressions and gestures will provide clues about the message you are trying to get across, even if (s)he finds the words hard to follow
• Use short sentences; allow plenty of time for her/him to absorb what you have said and to respond
• Be comfortable listening to periods of silence without feeling the need to speak
• Talk with a normal voice but at a slightly slower speed than usual
• Ask direct questions, for example 'Do you want a cup of tea?' rather than 'What would you like to drink?'
• Give only one piece of information at a time
• Check you have both understood. Do not pretend you have understood when you have not
• Repeat statements where necessary and emphasise key words
• If you are not understood the first time, try saying the same thing using alternative words
• Do not finish the person's statements for them. However, if they get stuck for long periods of time, help them to search for words
• Augment speech with gesture and visual aids where possible
• Have a pen and paper handy, as some people can read or write better than they can speak. Sometimes drawing the message or using other 'props' (pictures, photographs and real objects) can help
• Ask closed 'yes'/'no' questions as they are easier to answer than open questions that need a full answer
• Use gestures (thumbs up or down) or point to a symbol (tick, cross, smiley face, unhappy face) to check meaning, as it is common for people with aphasia to mix related words (such as 'yes' and 'no' or 'he' and 'she')

Wernicke's aphasia – where damage to the temporal lobe may result in a fluent aphasia. Affected individuals may speak in long sentences that have no meaning, add unnecessary words and even create new 'words'.¹⁸

Anomic aphasia – where people can understand speech well, but are left with a persistent inability to supply words for the things that they want to talk about. Sometimes the impairment can be so subtle that it only manifests itself when the patient is put into unfamiliar or stressful surroundings and the language consists of 'low frequency' words that (s)he would be unlikely to come across in everyday life.¹⁹

Aphasia affects each person differently and their communication difficulties can also change from day to day or even hour to hour. They are likely to be worse when tired or under pressure,²¹ and guidance from several aphasia associations recommend a number of strategies for communicating more effectively with people with aphasia.^{18,20,21} Table 4 outlines their recommendations. It is important to recognise and understand

the type of aphasia a person has and how it affects their communication, and to adapt techniques accordingly.

Dysarthria

Dysarthria is a collective name for a group of speech disorders resulting from neurogenic disturbances in muscular control and resultant paralysis, weakness or unco-ordination of the speech musculature.²² It can cause problems in both articulation and resonance for patients with a variety of different neurological conditions, including cerebral palsy, multiple sclerosis, motor neurone disease and stroke. All types of dysarthria affect the articulation of consonants, causing slurring of speech. This can be especially debilitating at a time when communication with friends, family and healthcare workers is vital.²³ The intelligibility of the dysarthria depends greatly on the extent of the neurological damage.

The specific type of dysarthria associated with Parkinson's disease is known as 'hypokinetic dysarthria'. Problems with articulation are paired with a characteristic mask-like facial expression due

to the rigidity of the facial musculature. Reduced respiratory support for speech and rigidity of the muscles of respiration results in reduced volume and a monotone, breathy, whispery or harsh voice quality.²⁴ The main features that make it distinct from other types of dysarthria are the difficulties experienced in initiating speech, which can lack fluency, with frequent pauses, word blocks, repetition of syllables and a sound or word followed by short rushes of speech. It is important to be aware that speech can be affected by the timings of Parkinson's medication.²⁵ Speech is easier to follow during the 'off periods', that is, while the medication is working and the symptoms are 'switched off' or at least reduced. Negotiating the optimum time for an appointment by pinpointing and avoiding problem times will aid communication.

Tips for the listener

Communicating with a person with dysarthria can be facilitated by following these guidelines:

- Ensure the person only does one thing at a time, as performing two tasks simultaneously (eg walking and talking) is difficult for people with neurological impairment
- Reduce distractions and background noise
- Give the person time to reply
- Watch the person as he or she talks and avoid writing notes simultaneously
- Let the speaker know when you have

difficulty understanding him or her and do not pretend to understand

- Repeat the part of the message that you understood so that the speaker does not have to repeat the entire message, only the bit you did not catch
- If you still do not understand the message, ask yes/no questions if possible; have the speaker write his/her message to you; or consider an alternative communication method.

Alternative or augmentive communication

When communication needs cannot be met through speech, non-verbal communication can help to reduce the frustration and stress of being unable to communicate. By alleviating the pressure to speak, alternative and augmentive communication (AAC) allows the person with speech difficulties to be more relaxed and come across in a more intelligible manner.

AAC aids include:

- Low technology devices – such as notebooks and pencil, charts with pictures, symbols, letters or words
- Wireless or wired amplification – which can be used to increase vocal loudness and decrease voice fatigue
- Email – using trackballs and mice (Fig. 6) designed for ease of operator use if there is associated spasticity of the limbs
- Specially adapted computers – which

may be programmed with voice recognition software or voice synthesisers

- Electronic voice output devices – for example light writers, which are small portable text-to-speech communication aids specially designed to meet the particular needs of people with speech loss and progressive neurological conditions (Fig. 7)
- Palatal lift devices²³ – a combination palatal lift and augmentation dental prosthesis with modified base-plate to improve articulation by lowering the palate to aid pronunciation of consonants, and by displacing the soft palate to eliminate the hyper-nasality and emission of air during the production of oral consonant sounds.

Some conditions associated with communication disorders are lifelong and are associated with learning disability or learning differences, such as autistic spectrum disorders.

Autistic spectrum conditions

Autism is a lifelong developmental disability that appears in infancy, typically within the first three years of life, and persists throughout life. It affects the areas of the brain controlling language, social interaction and creative and abstract thinking, and affects the way a person communicates with, and relates to, people and the world around them.²⁶ It is one of the range of disorders now referred to under the umbrella term 'autistic spectrum disorders' (ASD). The aetiology of ASD is unknown, but there is evidence of an inherited link,²⁷ and an association with other conditions such as birth trauma, tuberous sclerosis and fragile X syndrome.²⁸ There are over



Fig. 6 Individual using a mouse to operate the computer for communication by e-mail



Fig. 7 A lightwriter used as a text to speech communication aid by people with speech loss

half a million people with autism in the UK (1 in 100), with a male to female ratio of 3.5:1.²⁹ There is no cure for autism, and the treatment/management goal is to achieve independence in daily living activities and self-care, through specialist education, behavioural strategies and creation of a highly structured environment.²⁸ Medication is often used to manage age specific behavioural challenges.²⁷

Triad of impairments

ASD spans a continuum of severity of conditions. Classic autism is the most severe of the three commonest forms of ASD. In the middle is pervasive developmental disorder (PDD), a diagnosis given to people with more social activity, higher empathy and greater interaction and communication skills than autism. At the other end of the scale, children and adults with relatively normal language skills and intelligence, but who display poor social skills and decreased ability to show empathy, are given a diagnosis of Asperger's syndrome (AS).³⁰⁻³² All these conditions are defined by a combination of three things, referred to as 'the triad of impairments'.²⁸ These core features are:

- Qualitative impairment in reciprocal social interaction, especially relating to other people and understanding social situations
- Qualitative impairment in communication, particularly with verbal and non-verbal communication
- Qualitative differences in imagination, leading to literal interpretation of language.

As a result of these features there is a markedly restricted repertoire of activities and interests that can result in obsessive, repetitive behaviour and a strong resistance to change. These characteristics are described exceptionally well in Mark Haddon's novel *The curious incident of the dog in the night-time*, where the 15 year old 'detective and narrator' has Asperger's syndrome. He is described thus: 'He knows a very great deal about maths, and very little about human beings. He loves lists, patterns and the truth. He hates the colours yellow and brown and being touched. He has never gone further than the end of the road on his own...'³³

Life for a person with ASD has been described as 'a confusing, interacting mass of events, places, sounds and sight. There seems to be no clear boundaries, order or meaning to anything'.²⁶ This confusion arises partly from sensory differences,³⁴ resulting in either hypersensitivity or hyposensitivity to 'normal' stimuli of any of the sensory systems, including sound, touch, pain and light. These differences can interfere with daily living in many ways, ranging from failure to recognise a familiar environment if approached from a different direction, to finding it difficult to function in a noisy, crowded room. Sounds, visual stimuli or vestibular stimuli (such as strong smells) can cause pain, confusion and fear or panic, leading to an inability to cope in many situations.³⁵ For the individual with ASD, reaction to pain may vary from almost complete insensitivity, to an over-reaction to the slightest touch.³⁶ They may exhibit sensitivity to a bright or flickering light, over-reaction to hot and cold, intolerance of certain smells, especially cleaning fluids and perfumes,²⁶ and a painful reaction to loud or high noises, such as the telephone ringing or machinery operating. Sainsbury, a writer with AS, likens it 'to living with the volume of a particular sense being turned up too high'.³⁷

Behaviour

People with autism do not understand the unwritten social rules which most of us pick up without thinking, for example they may stand too close to another person or start an inappropriate subject of conversation. They have to learn what most of us know intuitively.³⁸

Their inability to interpret or predict the behaviour of others via tone of voice or facial expressions may lead to social conflict, isolation and engagement in solitary activities. For example, people with Asperger's syndrome commonly demonstrate unusual interest in systems that operate according to immutable rules – such as train timetables, numbers and letters, movements of the planets, escalators and elevators – that are pursued with great intensity.³⁸

It is worth exploring these interests during history taking, as sometimes they can be used to connect to the dental

environment, or as a reward for managing the dental situation.

Blackburn³⁹ describes life as being like watching 'a soap opera with the volume turned off and when the characters' actions become sudden and unpredictable, you cannot read their behaviour, which comes across as very threatening and frightening most of the time'. In search of 'stability' to provide reassurance and a coping mechanism, adults with ASD characteristically develop and depend on routines, rituals and continuity.²⁶ Such ritual behaviours include flapping hands, rocking, flicking fingers and grimacing. This seeking of stability may, in part, explain their resistance to change.

Despite looking calm, most people with ASD have anxiety levels that are normally verging on pathogenic. The sensitivities to stimuli mean individuals can easily reach a point of 'sensory overload' which can lead to them 'shutting down' and 'withdrawing'.³⁵ Sensory overload can also manifest itself as irritability, pacing up and down, covering ears with hands, or more challenging behaviour such as screaming, excessive spinning or rocking, head banging, self injury or destructiveness.³⁵

Communication

Cognitive impairment is evident in approximately 70% of people with autism and is severe in 40%.⁴⁰ Hence, completing tasks which require reasoning, interpretation, integration or abstraction is difficult for many people.⁴¹ However, it is important to remember that difficulty in the area of communication is a fundamental part of ASD itself. People with autism have difficulties with both verbal and non-verbal language. There is a very literal understanding of language and a tendency to think people always mean exactly what they say. People with ASD can find it difficult to use or understand facial expressions or tone of voice, jokes and sarcasm, and common phrases and sayings.⁴¹ Because of the inability to translate inference, language needs to be precise, exact and honest, or otherwise it will be interpreted as lying and trust will be lost. It has been said that people with ASD are lied to every day, and from their perspective this is the case.⁴²

Some people with autism have no, or fairly limited, speech. They will still usually understand what has been said to them, but may prefer to use alternative means of communication, such as sign language or visual symbols – with Makaton sign language⁴³ and the Picture Exchange Communication System⁴⁴ being the most commonly used. People with good language skills may still find it hard to understand the give-and-take nature of conversations, preferring to indulge in one-sided talk rather than back-and-forth conversation.²⁷ In addition, there may be persistent questioning, or confusion and use of made-up words (neologisms); involuntary repetition of what has just been heard (echolalia); repetition of things heard in the past, such as radio and television dialogue (delayed echolalia); or talking at length about their own interests. All these phenomena tend to obscure the meaning of their speech.³⁵

Meaningful communication can be encouraged by dealing with one idea at a time and providing reassurance that you have understood and do not need a repetition. An effective communication strategy is to agree a concrete means of showing whose turn it is to speak, for example the person holding the pen speaks, then hands it to other person when it is their turn to speak.²⁶ It also helps to speak in a clear, consistent way and give people with ASD time to process what has been said to them. Verbal communication is not always the best form and some people prefer a non face-to-face form of communication. In this situation email and text messages can be helpful.

Oral health

People with ASD are at higher risk of dental disease than the general population, due to the side effects of long-term medication, including xerostomia, gingival hyperplasia and caries;²⁷ the use of sweets as behavioural rewards; difficulties with oral hygiene; dietary limitations; and rigid individual food fads.²⁹ Additionally, dental attendance can be a major challenge for the individual and their carers/families. The combination of a busy waiting room, unfamiliar staff, lights shone at the face,

noisy equipment, the feel of cold instruments and water spray in the mouth, and the strong taste of mouthwash or toothpaste all have the potential to cause sensory overload and meltdown or challenging behaviour.⁴⁵

Provision of oral health care

ASD is common and it is likely that the dental team will encounter people with autism. An understanding of its characteristics and how to adapt to them enhances the delivery of oral care. Careful preparation for the dental visit that takes the communication and behavioural issues into account can help the individual, the carer/family and the dental team to cope.

Preparation for the visit

New experiences can be challenging for people with autism, but they need not be a problem if properly planned.⁴⁶ A leaflet designed to give patients, their carers/families and dentists the information they need prior to a dental visit can be downloaded from the National Autistic Society (NAS) website.⁴⁶ For patients, it recommends a preview or practice visit at a quiet time of the day to allow familiarisation with the dental environment, equipment and staff without receiving any treatment.

For carers, it advises compiling a 'social story book' of photos or pictures for use at home, to show the stages of visiting the dentist. It may start with leaving home and getting in the car, and should cover all the different steps so the person learns what is coming next so that there are no surprises. The NAS recommends including a 'reward picture' at the end (such as a favourite activity) so the patient knows there is something to look forward to. They also advise that in most situations, it is better to inform the individual of the visit as early as possible and use visual supports, such as a calendar, to chart the impending visit.

For dentists, the leaflet includes a tear-off sheet, which aims to identify any particular trigger areas which have caused problems previously whilst receiving dental treatment, or any particular phobias or fears such as moustaches, perfume, or particular colour clothing. It also asks questions about the preferred

and most effective method of communication for that person. Strategies such as allowing the person with autism to borrow non-essential equipment, such as a mirror and safety glasses, to allow them to examine them and desensitise their use in the safety of their own environment, increase the likelihood of a successful dental visit.⁴⁵

The visit

Routine is important for people with autism; it provides stability and helps them to cope. Creating a routine that is followed at every dental visit is valuable. This may involve the same route from home to the practice, into the practice and seeing the same staff in the same uniforms in the same surgery. The patient's carer will be able to provide guidance on the best means of communication for the individual, such as use of symbols and/or photographs and managing one concept at a time. They may bring pre-prepared simple relevant visual aids for use at the appointment. No matter how articulate an adult with a higher functioning ASD may appear to be, assume that they will struggle with some aspects of the consultation and take this into account in your approach.³⁵ The balance that needs to be achieved is to respect the patient as an adult and communicate directly with them, but to do so in a way that has meaning for that individual.

The *Learning resource on autistic spectrum conditions for primary care* advises practitioners to use clear, simple language with short sentences; avoid idioms, irony, metaphors and words with double meanings; and use direct requests.³⁵ For example, say 'Stand up please' rather than 'Can you stand up?' The latter may result in the person remaining seated or answering 'yes' because they have not realised they are being asked to do something. Also, it is important not to use gestures or facial expressions without verbal instructions, as these may not be understood. People with ASD rarely make eye contact, but this does not mean that they are not listening. They usually find it difficult to understand another person's perspective, and whilst they may not understand what you intend to do, they may expect you to know what

they are thinking. Also, it is important to ask for the information you need as they are unlikely to volunteer it without being asked.

The behaviour exhibited by an adult with an ASD will be affected by a number of factors, both directly and indirectly related to the appointment. Factors including their present state of health, the disruption caused to their routine by the appointment, the problems they may have encountered *en route*, and the stress at the social demands being placed on them,³⁵ precede the challenge of being examined and tolerating physical contact.

Minimising waiting times, by giving the first or last appointment of the day, reduces stress. If possible, find a small side-room or quiet area where the person and their carer/family can wait. They may prefer to wait outside, in the car, and be called in when the health professional is ready. If the appointment is likely to be delayed, the family may wish to leave the building completely and return at a later agreed time. Assistance or service dogs are increasingly being used by people with autism (particularly children and adolescents) to provide a calming influence, a sense of security when accessing different environments and affording the individual more independence and autonomy.⁴⁷ If an individual is accompanied by an assistance dog, it will need to be accommodated in the dental surgery during treatment.

Always keep background noise to a minimum and warn the patient before you touch them. It is essential to explain what you are doing and why in simple short sentences, and decide on a clear and agreed stop signal. It may be necessary to enlist the carer/parent's help, but it is important not to overload the patient with several people speaking at the same time.²⁷ The bright overhead light can be masked by providing tinted safety goggles and the noise of the handpieces can be camouflaged using a walkman, or earplugs if the patient prefers.⁴⁵ Other tactics that help the person to cope include the use of a time indicator such as visual sand-timer or a watch alarm to help them realise that the experience has a time limit, and use of a stress ball or comforter as a distractor.



Fig. 8 Ritualistic behaviour of hand-flapping to achieve stability associated with autism

During treatment some patients might withdraw, ie put their fingers in their ears or use other 'stim', such as flapping their hands, flicking their fingers, rocking or making noises (Fig. 8). This kind of behaviour is calming to the individual, helps them to cope and should not be stopped unless absolutely essential.⁴⁵

People can have an atypical hypersensitive or hyposensitive response to pain and may have an unusual response to pain such as laughter, humming or singing.³⁵ It is important to ask the patient to report any pain, to believe what they say and respond accordingly.

Whatever the cause of communication differences, strategies for success all rely on knowledge of the individual patient and the ability to tailor your approach to their needs and anxieties so that potential problem areas and triggers for overload can be avoided.

The illustrative material used in Figures 2, 3, 4, 5, 6 and 8 is credited to www.JohnBirdsall.co.uk.

1. Fiske J. Are you fluent in jargonese? *The Probe* 1993; **April**: 22-23.
2. Wanless M. Communication in dentistry - why boover. *Oral Health Report* 2007; **1(2)**: 2-5.
3. Office of National Statistics. *UK adult dental health survey: oral health in the United Kingdom 1998*. Preliminary release. London: Office of National Statistics, 1999, publication no. ONS (99) 302. <http://www.statistics.gov.uk/pdfdir/dh0999.pdf>
4. Champion J, Holt R. Dental care for children and young people who have a hearing impairment. *Br Dent J* 2000; **189**: 155-159.
5. Mulus N B, Birol A. Effects of Behçet's disease on

hearing thresholds and transient evoked otoacoustic emissions. *J Otolaryngol* 2007; **36**: 220-226.

6. D'Mello J, Kumar S. Audiological findings in cleft palate patients attending speech camp. *J Med Res* 2007; **125**: 777-782.
7. Royal National Institute for Deaf People website. 2008. www.rnid.org.uk
8. Royal Association for Deaf People website. 2008. www.royaldeaf.org.uk
9. Fiske J, Dickinson C, Boyle C, Rafique S, Burke M. Managing the patient with a sensory disability. In *Special care dentistry*. pp 27-42. London: Quintessence Publishing, 2007.
10. Mahoney E, Kumar N, Porter S. Effect of visual impairment upon oral health care: a review. *Br Dent J* 2008; **204**: 63-67.
11. The Royal National Institute of Blind People website. 2008. www.rnib.org.uk
12. Deafblind UK website. 2008. www.deafblind.org.uk
13. Murdoch B E (ed). *Dysarthria - a physiological approach to assessment and treatment*. Chapter 1. Queensland: Nelson Thornes, 1998.
14. American Speech-Language-Hearing Association website. 2008. www.asha.org
15. Code C, Hemsley G, Herrmann M. The emotional impact of aphasia. *Semin Speech Lang* 1999; **20**: 19-31.
16. Code C, Mackie N, Armstrong E, Stiegler L. The public awareness of aphasia: an international survey. *Int J Lang Commun Disord* 2001; **36** (Suppl): 1-6.
17. Simmons-Mackie N, Code C, Armstrong E. What is aphasia? Results of an international survey. *Aphasiology* 2002; **16**: 837-848.
18. National Aphasia Association. Aphasia facts menu webpage. http://www.aphasia.org/Aphasia%20Facts/aphasia_faq.html (accessed 30 May 2008).
19. Jordan L, Kaiser W. Aphasia: a social approach. Chapter 1. London: Chapman & Hall, 1996.
20. Stroke Recovery Canada. Aphasia, communication and stroke webpage. <http://www.strokrecovery-canada.com/srcEnglish/english/aphasianewsletter.asp> (accessed 30 May 2008).
21. Speakability. Aphasia information webpage. http://www.speakability.org.uk/Pages/Aphasia_%20Information/Aphasia_Information.htm (accessed 30 May 2008).
22. Darley F, Aronson A, Brown J R. Differential diagnostic patterns of dysarthria. *J Speech Hear Res* 1969; **12**: 246-269.
23. Esposito S, Mitsumoto H, Shanks M. Use of palatal lift and palatal augmentation prostheses to improve dysarthria in patients with amyotrophic lateral sclerosis: a case series. *J Prosthet Dent* 2000; **83**: 90-98.
24. Miller N, Noble E, Jones D, Burn D. Life with communication changes in Parkinson's disease. *Age Ageing* 2006; **35**: 235-239.
25. De Letter M, Santens P, Estercam I et al. Levodopa-induced modifications of prosody and comprehensibility in advanced Parkinson's disease as perceived by professional listeners. *Clin Linguist Phon* 2007; **10**: 783-791.
26. National Autistic Society website. 2008. www.autism.org.uk
27. Friedlander A H, Yagiela J A, Paterno V I, Mahler M E. The neuropathology, medical management and dental implications of autism. *J Am Dent Assoc* 2006; **137**: 1517-1527.
28. Scottish Society of Autism website. 2008. www.autism-in-scotland.org.uk
29. Fiske J, Dickinson C, Boyle C, Rafique S, Burke M. Managing patients with a learning disability. In *Special care dentistry*. pp 43-54. London: Quintessence Publishing, 2007.
30. Jones A, Cork C, Chowdhury U. Autistic spectrum disorders. 2: diagnosis and management. *Community Pract* 2006; **79**: 128-130.
31. Jones A, Cork C, Chowdhury U. Autistic spectrum disorders. 1: presentation and assessment. *Community Pract* 2006; **79**: 97-98.
32. Spence S J, Sharifi P, Witznitzer M. Autism spectrum disorder: screening, diagnosis, and medical

- evaluation. *Semin Pediatr Neurol* 2004; **11**: 186-195.
33. Haddon M. *The curious incident of the dog in the night-time*. Back cover. London: Vintage, 2004.
 34. Bogdashina O. *Sensory perceptual issues in autism and Asperger syndrome. Different sensory experiences - different perceptual worlds*. pp 25-44. London: Jessica Kingsley Publishers, 2003.
 35. NHS Education for Scotland. Learning resource on autistic spectrum disorders for GPs and primary care practitioners. NHS Education for Scotland, 2006. www.nes.scot.nhs.uk/asd/index.htm
 36. Jordan R, Powell S. *Understanding and teaching children with autism*. Chichester: John Wiley, 1995.
 37. Sainsbury C. *Martian in the playground: understanding the schoolchild with Asperger's syndrome*. Chapter 2. Bristol: Lucky Duck Publishing, 2000.
 38. Cohen S B. The cognitive neuroscience of autism. *J Neurol Neurosurg Psychiatry* 2004; **75**: 945-948.
 39. Caldwell P. *Finding you finding me*. Chapter 3. London: Jessica Kingsley Publishers, 2005.
 40. Newschaffer C, Croen L, Daniels J, Giarelli E. The epidemiology of autism spectrum disorders. *Ann Rev Public Health* 2007; **28**: 235-258.
 41. Filipek P, Accardo P, Ashwal S *et al*. Practice parameter: screening and diagnosis of autism: report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology* 2000; **55**: 468-479.
 42. Beardon L. *Autism as a spectrum disorder*. Lecture presented at British Society for Disability and Oral Health Winter Scientific Meeting, 9 December 2005.
 43. Makaton website. 2008. www.makaton.org
 44. Pyramid Educational Consultants. PECS communication books and boards webpage. www.pecs.org.uk/shop/asp/prodtype.asp?prodtype=7 (accessed 30 May 2008).
 45. National Autistic Society website. Dentist: preparing for a visit. www.nas.org.uk/nas/jsp/polopoly.jsp?d=1064&ta=7844 (accessed 30 May 2008).
 46. Golding M. *Dental care and autism*. Downloadable leaflet. www.nas.org.uk/content/1/c4/86/15/dentalcareandautismfinal2.pdf
 47. Autism Service Dogs of America website. 2008. www.autismservicedogsofamerica.com