GUIDELINES

Challenging behaviour and learning disabilities: summary of NICE guidance

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This is one of a series of *TheBMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists.

Further information about the guidance, a list of members of the guideline development group, and the supporting evidence statements are in the full version on thebmj.com.

It is relatively common for people with a learning disability to develop behaviour that challenges. In educational, health, and social care settings, prevalence rates of challenging behaviour in people with learning disabilities vary from 10% to 15%,[1 2] with rates peaking between the ages of 20 and 49 years. Rates are higher in people with more severe disabilities and within inpatient settings.[1] Behaviour that challenges includes aggression, self injury, stereotypic behaviour, and withdrawal, which often result from the interaction of personal and environmental factors. Such behaviour can have detrimental consequences for the person, including lower quality of life, restrictive practices, physical abuse, and out of area placements.[1]

This article summarises the most recent recommendations from the National Institute for Health and Care Excellence (NICE) on challenging behaviour and learning disabilities in adults, children, and young people.[3]

Recommendations

NICE recommendations are based on systematic reviews of the best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the Guideline Development Group's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are in the full version of this article on thebmj.com.

General principles of care

Working with people with a learning disability and behaviour that challenges, and with their families and carers

- When providing support and interventions:
  - Take into account the severity of people's learning disability and their developmental stage, any communication difficulties, and physical or mental health problems
  - Aim to provide support and interventions in the least restrictive setting (such as the person's home or in other places where the person regularly spends time)
  - Aim to prevent, reduce, or stop the development of future episodes of behaviour that challenges
  - Offer support and interventions respectfully and aim to improve quality of life
  - Ensure that the focus is on improving people's support and increasing their skills rather than changing people
  - Ensure that people know whom to contact if they are worried about care or interventions, including their right to a second opinion
  - Offer independent advocacy to the person and to family members or carers.

Team working

- If initial assessment and management have not been effective, or the person has more complex needs, health and social care provider organisations should ensure that teams providing care have prompt and coordinated access to specialist assessment, support, and intervention services. These services should provide advice, supervision, and training from a range of staff to support any care or intervention, including psychologists, psychiatrists, behavioural analysts, nurses, social care staff, speech and language therapists, educational staff, occupational therapists, physicians, paediatricians, and pharmacists.

Staff training, supervision, and support

- Health and social care provider organisations should ensure that all staff working with people with a learning disability and behaviour that challenges are trained to deliver proactive strategies to reduce the risk of this behaviour, including:
  - Developing personalised daily activities
  - Adapting a person's environment and routine
  - Helping the person develop an alternative behaviour to achieve the same purpose by developing a new skill (for example, improved communication or emotional regulation)
  - Involving people and their family members or carers in planning support and interventions
  - Using strategies designed to calm and divert people who show early signs of distress
  - Delivering reactive strategies.

HOW PATIENTS WERE INVOLVED IN THE CREATION OF THIS ARTICLE

Three lay committee members with specific knowledge and experience of challenging behaviour in people with a learning disability contributed to the formulation of the recommendations summarised in this article. People with learning disabilities and carers of people with learning disabilities and behaviour that challenges took part in focus groups that informed the development of recommendations summarised in this article.

THE BOTTOM LINE

- Include the person with learning disabilities and his or her family and carers in assessments and interventions
- Undertake functional assessments and implement behaviour support plans linked to these
- Provide the least restrictive behavioural, cognitive behavioural, and psychosocial interventions, as close to home as possible
- Reserve drugs as a treatment option for severe aggression or self injury, and only in combination with a behavioural, cognitive behavioural, or psychosocial intervention
- Aim to increase quality of life as well as reducing behaviour that challenges

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Previous articles in this series

- Diagnosis and management of depression in children and young people: summary of updated NICE guidance (*BMJ* 2015;350:h824)
- Irritable bowel syndrome in adults in primary care: summary of updated NICE guidance (*BMJ* 2015;350:h701)
- Antenatal and postnatal mental health: summary of updated NICE guidance (*BMJ* 2014;349:g7394)
- Diagnosis and management of community and hospital acquired pneumonia in adults: summary of NICE guidance (*BMJ* 2014;349:g6722)
- Intrapartum care of healthy women and their babies: summary of updated NICE guidance (*BMJ* 2014;349:g6886)

Support and interventions for family members or carers

- When providing support to family members or carers (including siblings):
  - Recognise the impact of living with or caring for a person with a learning disability and behaviour that challenges
  - Explain how to access family advocacy
  - Consider family support and information groups if there is a risk of behaviour that challenges or if it is emerging
  - Consider formal support through disability specific support groups for family members or carers and regular assessment of the extent and severity of the behaviour that challenges
  - Provide skills training and emotional support to help family and carers take part in and support interventions.

Early identification of the emergence of initial behaviour that challenges

- Everyone involved in caring for and supporting people with a learning disability (including family members and carers) should understand the risk of behaviour that challenges and that it often develops gradually. Pay attention to and record factors that may increase this risk, including:
  - Personal factors, such as:
    - A severe learning disability
    - Autism
    - Dementia
    - Communication difficulties (expressive and receptive)
    - Visual impairment (which may lead to increased self injury and stereotypy)
    - Physical health problems
    - Variations with age (peaking in the teens and 20s).
  - Environmental factors, such as:
    - Abusive or restrictive social environments
    - Environments with too little or too much sensory stimulation and those with low engagement levels (for example, little interaction with staff)
    - Developmentally inappropriate environments (for example, a curriculum that makes too many demands on a child or young person)
    - Environments where disrespectful social relationships and poor communication are typical, or where staff do not have the capacity or resources to respond to people's needs
    - Changes to the person's environment (for example, major staff changes or a move to a new care setting).

Physical healthcare

- GPs should offer an annual physical health check to children, young people, and adults with a learning disability in all settings, using a standardised template (such as the Cardiff health check template).[4] Undertake this with a family member, carer, healthcare professional, or social care practitioner who knows the person and include:
  - A review of any known or emerging behaviour that challenges and how it may be linked to any physical health problems (such as hearing impairment or pain—for example, toothache)
  - A physical health review
  - A review of all current health interventions, including drugs and related side effects, adverse events, and drug interactions and adherence
  - An agreed and shared care plan for managing any physical health problems (including pain).

Assessment

The assessment process

- When assessing behaviour that challenges, ensure that:
  - The person being assessed remains at the centre of concern and is supported throughout the process, and that family members and carers are fully involved
  - All personal and environmental factors (past and current) that may lead to behaviour that challenges are taken into account
  - Assessment is a flexible process, because factors that trigger and maintain behaviour may change over time
  - Assessments are reviewed after any serious change in behaviour
  - Assessments focus on the outcomes of reducing behaviour that challenges and improving quality of life
  - The resilience, resources, and skills of family members and carers are taken into account
  - The capacity, sustainability, and commitment of the staff delivering the behaviour support plan are taken into account.

Risk assessment

- Assess and regularly review the following areas of risks during any assessment of behaviour that challenges:
  - Suicidal ideation, self harm (particularly in people with depression), and self injury
  - Harm to others
  - Self neglect
  - Breakdown of family or residential support
  - Exploitation, abuse, or neglect by others
  - Rapid escalation of the behaviour that challenges.

Ensure that the behaviour support plan includes risk management.

Functional assessment of behaviour

- Vary the complexity and intensity of the functional assessment according to the complexity and intensity of the behaviour that challenges, following a phased approach as set out below:
  - Gather pre-assessment data to help shape the focus and level of the assessment
  - For recent onset behaviour that challenges, consider brief structured assessments such as the Functional Analysis Screening Tool[5] or Motivation Assessment Scale[6] to identify associations between the behaviour and what triggers and reinforces it
  - Take into account whether any important changes to the person's environment and physical or psychological health are associated with the development or maintenance of recent onset behaviour that challenges or marked changes in

patterns of existing behaviours
  - Consider in-depth assessment involving interviews with family members, carers, and others; direct observations; structured record keeping; questionnaires; and reviews of case records
  - If a mental health problem might underlie behaviour that challenges, consider initial screening using assessment scales such as the Diagnostic Assessment Schedule for the Severely Handicapped-II,[7] Psychiatric Assessment Schedule for Adults with a Developmental Disability,[8] or the Psychopathology Instrument for Mentally Retarded Adults[9] and seek expert opinion.

Psychological and environmental interventions

Early intervention for children and their parents or carers

- Consider parent training programmes for parents or carers of children with a learning disability who are aged under 12 years with emerging, or at risk of developing, behaviour that challenges.

Interventions for behaviour that challenges

- Consider personalised interventions that are based on behavioural and cognitive behavioural principles and a functional assessment of behaviour, are tailored to the range of settings in which they spend time, and consist of:
  - Clear targeted behaviours with agreed outcomes
  - Assessment and modification of environmental factors that could trigger or maintain the behaviour (for example, altering task demands for avoidant behaviours)
  - Addressing staff and family member or carer responses to behaviour that challenges
  - A clear schedule of reinforcement of desired behaviour and the capacity to offer reinforcement promptly
  - A specified timescale to meet intervention goals (modifying intervention strategies that do not lead to change within a specified time).

Drugs

- Consider antipsychotic drugs to manage behaviour that challenges, only in combination with psychological or other interventions, and only if:
  - Psychological or other interventions alone do not produce change within an agreed time, or
  - Treatment for any coexisting mental or physical health problem has not led to a reduction in the behaviour, or
  - The risk to the person or others is severe (for example, because of aggression or self injury).

Overcoming barriers

There are three major barriers to effective implementation of this guideline. The first is the currently inadequate structure and resourcing of services, including the specialist community learning disability team. The capacity to deliver services is also severely hindered by the lack of appropriate support close to people's homes. Limitations in staff competency and high quality training present a third major barrier. Lack of training can lead to poor recognition of the behaviour that challenges and the underlying causes of that behaviour, as well as limited skills and knowledge in implementing appropriate treatment plans. Failure in these areas leads to over-reliance on drugs, which for many people will have limited effectiveness and may lead to serious side effects.[10 11]

10-MINUTE CONSULTATION

Gradual loss of vision in adults

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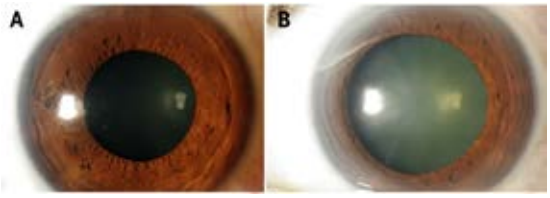
CPD/CME

Link to this article online for CPD/CME credits

A 70 year old man presents with gradual blurry vision in both eyes. He has recently noticed increasing glare when looking at lights.

What you should cover

Gradual loss of vision has many causes, and cataract is one of the most common causes in this age group. A logical history and examination can help to exclude sinister causes that require urgent treatment.



Photographs illustrating the iris and pupil during ophthalmic examination in (A) a normal eye and (B) an eye with a moderate nuclear sclerotic cataract

THE BOTTOM LINE

- Although cataract is a common cause of gradual vision loss in older patients, consider other treatable red flag conditions in this age group, such as giant cell arteritis, macular degeneration, retinal detachment, and vitreous haemorrhage, and refer urgently if you suspect these
- Do not refer patients for cataract surgery if their cataracts do not affect their daily life or if they are not keen to have surgery

History

How quickly has your vision become blurry?—Sudden visual loss within weeks is unlikely to be caused by age related cataract. Symptoms of age related cataract usually develop over months to years.

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This is part of a series of occasional articles on common problems in primary care. *The BMJ* welcomes contributions from GPs.

Box 1 | Referral for cataract surgery

Avoid referral if:

The patient is not keen to have surgery

The symptoms do not impinge on the patients' activities of daily living

The patient's overall prognosis is poor, owing to other comorbidities

There are medical contraindications to surgery, including poorly controlled diabetes, hypertension, or coagulation profile

Does the blurring affect only part of your vision?—Patients who describe a central dark spot probably have wet age related macular degeneration and require urgent ophthalmic referral. Consider intracerebral or glaucomatous causes of visual loss in patients with bilateral field defects.

Do you have any other changes to your vision?—New floaters or flashing lights (suggesting posterior vitreous detachment, retinal detachment, or a vitreous haemorrhage) or visual changes that cause the patient to note the bending of straight lines (suggesting wet age related macular degeneration) require urgent ophthalmic referral. Other symptoms associated with cataracts include progressive myopia, glare when looking at lights (cortical), worsening of reading vision out of proportion to distance vision (posterior subcapsular).

Are your eyes affected in any other way?—Pain, photophobia, and redness are not associated with cataract and suggest corneal disease—for example, infective keratitis or inflammatory conditions, such as uveitis.

Do you have any symptoms elsewhere?—Ask about systemic symptoms because giant cell arteritis may cause vision loss in this age group. Ask specifically about temporal headache, pain on chewing, new fatigue, fever-like symptoms, and myalgia (especially at the hips and shoulders).[1] If there are any doubts, start the patient on glucocorticoids and refer urgently to an ophthalmologist.

How does it affect your daily activities?—Particularly useful activities to ask about are reading, watching television, playing sports (such as golf or bowls), and driving.

Examination

Visual acuity—Measure visual acuity using a Snellen chart. Improvement in the visual acuity when a pin hole is used suggests a refractive cause of visual loss.

Cornea and conjunctiva—Conjunctival redness is usually caused by conditions such as conjunctivitis and iritis, rather than cataract. A new corneal opacity suggests an infective lesion. If corneal disease is suspected, use fluorescein drops illuminated by the ophthalmoscope's blue light to highlight corneal epithelial damage. If found, refer urgently to an ophthalmologist.

Red reflex—Check the red reflex at 1 m through the ophthalmoscope. A cataract will obscure this.

Pupils—Using an ophthalmoscope light, first check the direct and consensual pupil responses, then steadily swing the ophthalmoscope beam between the eyes. If a relative afferent pupillary defect is present, the affected pupil will dilate when light is shone on it, suggesting optic nerve disease, rather than cataract alone. This warrants ophthalmologic review. Ideally perform the remainder of the examination with pupil dilatation by instilling tropicamide (1%) into each eye.

Lens—Adjust the ophthalmoscope lens to +10 dioptres and assess the anterior segment from close up through the ophthalmoscope. In the normal eye the pupil will remain dark when the ophthalmoscope light is shone (fig A). A cataract usually appears as whiteness in the pupil (fig B).

Retinal examination—Set the ophthalmoscope to zero. While examining the retina, turn the ophthalmoscope lens towards the positive lenses if the patient is long sighted and towards the negative lenses if the patient is short sighted, until the retinal view is clear. If the disc looks pale or cupped, consider glaucoma or optic nerve disease. Haemorrhages in the central retina are associated with wet macular degeneration and warrant urgent ophthalmic referral. Scattered haemorrhages associated with yellow exudates suggest retinal vein occlusion or diabetic retinopathy. Check for diabetic and cardiovascular risk factors and refer to an ophthalmologist.

What you should do

Refer urgently to an ophthalmologist if there is sudden loss of vision (suggesting branch retinal arterial or vein occlusion, or vitreous haemorrhage), a central dark spot affecting vision or new visual distortion (wet macular degeneration), new flashes or floaters (retinal detachment), marked pain or photophobia (iritis, corneal ulcer), or systemic features suggestive of giant cell arteritis associated with visual disturbance, including a temporal headache, jaw claudication, new fatigue, and myalgia.

Refer non-urgently if there is a gradual onset of blurriness of vision associated with glare, progressive short sightedness, or if the patient has developed a gradual onset loss of part of the field of vision.

If cataract is suspected, explain that a cataract is a clouding of the lens near the front of the eye that causes blurred vision and offer possible referral for surgery as appropriate (box 1). Explain that cataract surgery entails the extraction of the old cloudy lens and replacement with a new clear artificial lens. The operation takes about 30 minutes and is usually performed under local anaesthetic (see box 2 for more details).

Driving advice—UK driving standards require patients to have a Snellen chart measurement of at least 6/12 with both eyes open and full spectacle or contact lens correction.[2] Ask patients to contact the Driver and Vehicle Licensing Authority if they are driving and do not reach this standard.

HOW PATIENTS WERE INVOLVED IN THE CREATION OF THIS ARTICLE

In the process of writing this article we sought the opinions of patients who had recently undergone cataract surgery. They were asked what they would have liked to have known before the surgery. Their responses were taken into account when writing box 2. They were also asked what symptoms have improved since their surgery. Their input was used to modify the history section.

Box 2 | Information on cataract surgery

Before surgery on the first eye patients undergo an assessment at the eye clinic. The new intraocular lens is usually selected to provide either good near or distance vision without the need for spectacle correction. In some settings it may be possible to have an intraocular multifocal lens that allows the patient to focus over a range of distances. The patient's refractive requirements are usually discussed with the ophthalmologist during the assessment.

Cataract surgery takes around 30 minutes and is usually performed under local anaesthesia. After surgery, 90% of patients will have a vision of 6/12 or better. Rare complications include: one person in every 1000 going blind in that eye as a direct result of the operation, and one in 10 000 losing the operated eye. There is virtually no risk to the other eye.[3]

The most common postoperative complications are redness, bruising of the eyelids, pain, and foreign body sensation. The most serious complication is intraocular infection (endophthalmitis), which is seen in 0.1% of operations and is usually accompanied by increasing redness, pain, floaters, or vision loss.

After the operation, patients are asked to avoid strenuous activity for two weeks and heavy lifting for four weeks because the incisions in cataract surgery are self sealing and need time to heal. Patients are usually asked to use antibiotic drops (such as chloramphenicol) four times a day for one week after the operation and corticosteroid drops such as dexamethasone (0.1%) and prednisolone (1%) four times a day for four weeks.