NICE National Institute for Health and Care Excellence

NICE Pathways

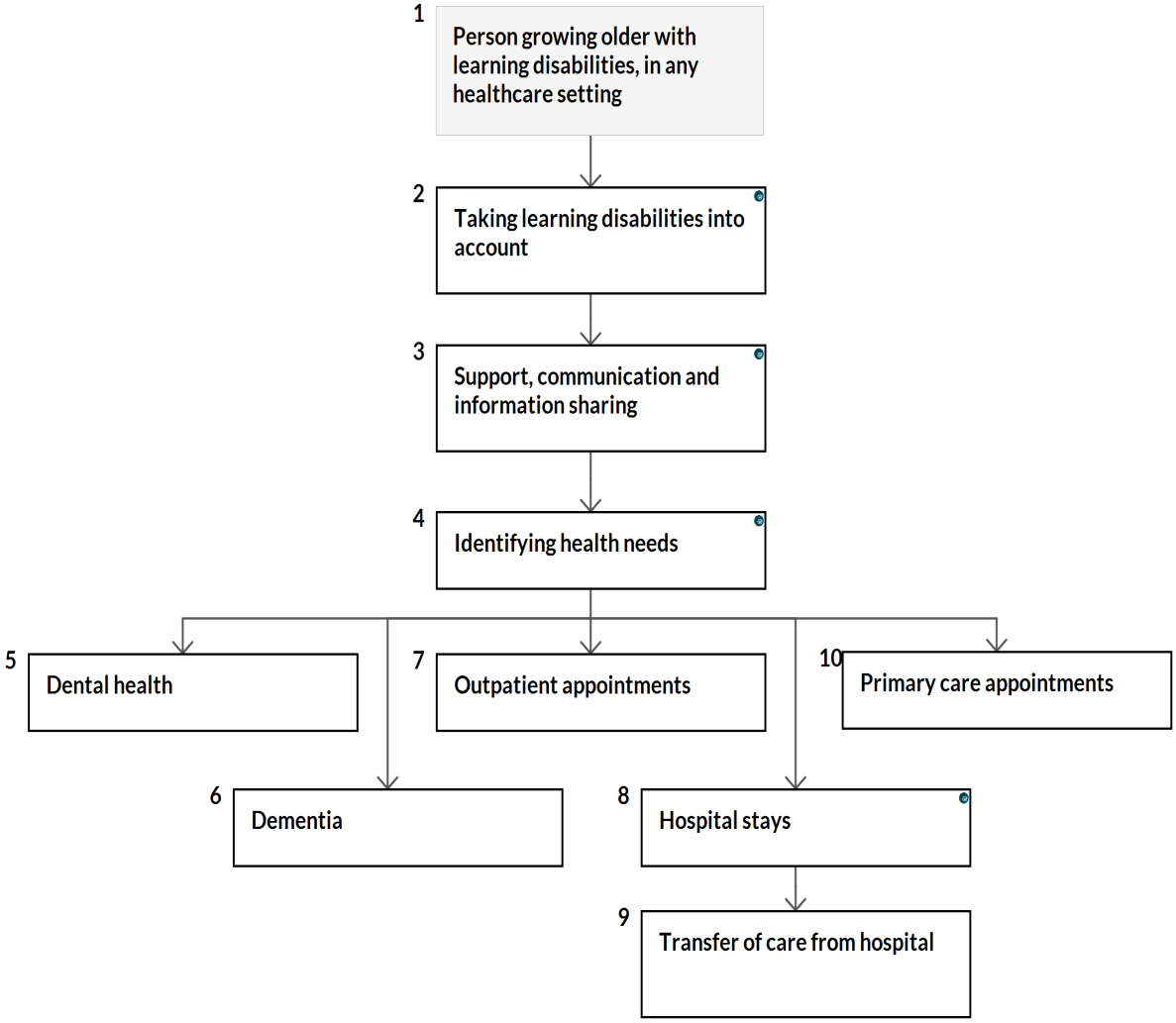
Health needs of people growing older with learning disabilities

NICE Pathways bring together everything NICE says on a topic in an interactive flowchart. NICE Pathways are interactive and designed to be used online.

They are updated regularly as new NICE guidance is published. To view the latest version of this NICE Pathway see:

http://pathways.nice.org.uk/pathways/care-and-support-of-people-growing-older-with-learning-disabilities
NICE Pathway last updated: 30 October 2020

This document contains a single flowchart and uses numbering to link the boxes to the associated recommendations.



1 Person growing older with learning disabilities, in any healthcare setting

No additional information

2 Taking learning disabilities into account

Practitioners carrying out assessments of care and support needs should be alert to any changes in the person's usual behaviour. This could include how they are communicating or their activity levels, and symptoms (such as weight loss, changes in sleeping patterns or low mood) that could show something is wrong or they are unwell.

Be aware that people growing older with learning disabilities [See page 10] might have difficulty communicating their health needs. When their needs change, think about whether these changes could be age-related and do not assume they are due to the person's learning disability or pre-existing condition ('diagnostic overshadowing').

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

1. Person-centred needs assessment

3 Support, communication and information sharing

Healthcare practitioners should encourage people growing older with learning disabilities [See page 10] to choose a family member, carer or advocate to bring with them to medical examinations and appointments if they would like this support.

Explain clearly to people with learning disabilities what will happen during any medical appointments as well as their likely follow-up care. In line with the Mental Capacity Act 2005, healthcare practitioners must take all reasonable steps to help the person understand this explanation.

As well as explaining to people beforehand what will happen, continue to explain what is happening throughout the appointment and ensure there is enough time set aside to do this. If the person agrees, also explain to their family member, carer or advocate what will happen.

Managers in healthcare settings should identify a single lead practitioner to be the point of contact for people with learning disabilities and their family members, carers and advocates. This practitioner could be a member of the community learning disability team or a nurse with experience in learning disabilities.

Ensure that everyone involved in the person's care and support shares information and communicates regularly about the person's health and any treatment they are having, for example by holding regular multidisciplinary meetings. Involve the person in all discussions.

Primary and secondary healthcare teams should identify at least 1 member of staff who develops specific knowledge and skills in working with people with learning disabilities and acts as a champion, modelling and sharing good practice. Use the expertise of people with learning disabilities to ensure the champion understands their needs.

Record a person's learning disability and any reasonable adjustments in their health records and share this information when making referrals. With the person's consent, make sure all relevant practitioners in community and acute settings can access this. Also record any specific needs or wishes, for example to do with the person's communication or mobility.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

2. Named lead practitioner

4 Identifying health needs

Recognise that people with learning disabilities may need additional health surveillance to help them identify and communicate symptoms of age-related conditions.

Offer annual health checks to older people with learning disabilities as long as these are followed by prompt referral to specialist services wherever needed. Explain what annual health checks involve and how to arrange them. Record any actions identified by the annual health check in the person's health action plan.

Offer older people with learning disabilities the same routine screening and health checks as other older people.

Discuss with people the changes that may occur with age. Ask them about and monitor them for

symptoms of common age-related conditions or changes in any existing conditions, including:

- blood pressure and cholesterol
- cancer
- dementia (also see dementia [See page 6])
- diabetes
- dysphagia (difficulty swallowing)
- epilepsy
- hearing loss and sight problems
- incontinence
- osteoporosis
- malnutrition
- menopausal symptoms
- mental health, including depression
- thyroid problems.

See the NICE Pathways on mental wellbeing and independence in older people, mental health problems in people with learning disabilities and depression.

Annual health checks

During a person's annual health check, give them information about other available services, including a care and support assessment under the Care Act 2014 if they have not already had one.

During a person's annual health check, ask if they are registered with a dentist, how often they see the dentist and check that they understand the importance of looking after their teeth and mouth.

Give people clear, accessible and practical information and advice about keeping well as they grow older. Tell them about, and help them access, services such as breast screening, smear tests, testicular and prostate checks, dental checks, hearing and sight tests, and podiatry.

Hearing assessments

Consider referring people with a diagnosed learning disability to an audiology service for a hearing assessment when they transfer from child to adult services, and then every 2 years.

See the NICE Pathway on hearing loss.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

4. Annual health check

5 Dental health

Dental practices should ensure their services are accessible to people with learning disabilities, for example by:

- reminding people about their appointments by phone
- sending letters in an accessible format, for example Easy Read
- suggesting that the person brings a carer or supporter with them
- ensuring staff have the skills to communicate with people with learning disabilities and put them at ease.

See the NICE Pathways on:

- oral and dental health
- oral health for adults in care homes.

6 Dementia

Explain at an early stage to people with learning disabilities (particularly people with Down's syndrome) and their family members, carers and advocates about the link between learning disabilities and dementia. Explain the signs of dementia, how it usually progresses and what support is available. Give people:

- printed information on dementia
- opportunities for one-to-one discussion with a professional
- advice on communication strategies for people with dementia.

Commissioners should ensure information is provided to family members, carers and advocates of people with learning disabilities who are being assessed for, or have been diagnosed with dementia. Consider also providing training. Information and training might cover:

- types of dementia
- how dementia might present in people with different learning disabilities

- care pathways for different dementias
- practical steps to manage daily life
- communication skills
- how to find further advice and ongoing support, including support groups and respite services (short breaks).

See also the NICE Pathway on dementia.

7 Outpatient appointments

Hospitals should offer an opportunity for the person and a family member, carer or advocate to visit the hospital before their outpatient appointment to meet the staff who will conduct any tests or examinations, see the equipment that will be used and identify what adjustments will be needed.

8 Hospital stays

When planning a hospital admission, arrange a pre-admission planning meeting, including the hospital liaison team or liaison nurse, a representative of the community learning disability team, the person and their family members, carers or advocate. At this meeting:

- complete the pre-admission documentation, which should include information from the person's hospital passport (for more information see NHS choices's page on hospital passports)
- discuss any reasonable adjustments needed, for example, arranging for the person to visit the hospital before their admission to meet the learning disability liaison nurse who will be their contact.

Hospitals should actively encourage staff to use pre-admission documents and flagging systems so that all relevant hospital staff know about the person's learning disability. At discharge, review how well this is working.

Hospitals should develop policies and guidance to enable someone chosen by the person to stay with them throughout their inpatient stay, including overnight.

Hospital staff should continue to offer health and personal care (toileting, washing, nutrition and hydration) to people with learning disabilities even if they have a family member, carer or advocate there to support them.

For further guidance on planning admission and admitting adults with identified social care needs to hospital, see the NICE Pathway on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

Quality standards

The following quality statement is relevant to this part of the interactive flowchart.

5. Hospital admissions

9 Transfer of care from hospital

If the person agrees, invite family members, carers or advocates to pre-discharge meetings, as well as the person themselves.

If the discharge plan involves support from family members or carers, take into account their:

- willingness and ability to provide support
- circumstances, needs and aspirations
- relationship with the person
- need for respite (short breaks).

Give the person (and their family members and carers) an accessible copy of their discharge plan when they are discharged, and make sure their GP has a copy within 24 hours. Make sure everyone knows what will happen next in the person's care and support.

After the person is discharged, the hospital learning disability liaison nurse, community learning disability team and primary care practitioners should work together to provide ongoing support to help the person manage their health condition.

For further guidance on discharging adults with identified social care needs from hospital, see the NICE Pathway on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

10 Primary care appointments

Primary care and community services should aim to ensure that older people with learning disabilities can see the same GP and other healthcare practitioners, wherever possible, to help

practitioners:

- become familiar with the person's medical history, which the person may have difficulty remembering themselves
- build good relationships and understand the person's usual behaviour and communication needs.

General practices should allocate a named member of staff to remind people with learning disabilities about appointments for screening and health examinations. This staff member should help the person attend the appointment by:

- using each person's preferred method of communication
- giving them information in a way they can understand
- ensuring the person understands the reason for the appointment and why it is important
- finding out their transport needs
- making reasonable adjustments to help the person and their carer or supporter to attend.

If the person is diagnosed with a health condition, give them and their family members, carers or advocate accessible information on the following (taking time to explain it to them as well):

- symptoms and management
- benefits, and potential side effects, of treatment
- how to take their prescribed medicines.

Support people to manage their own health conditions by getting to know them and adapting health advice to suit their personal choices and the activities they already enjoy (for example, playing football).

For the purpose of these recommendations a learning disability is defined as meeting 3 core criteria:

- lower intellectual ability (usually an IQ of less than 70)
- significant impairment of social or adaptive functioning
- onset in childhood.

A person's learning disability may be mild, moderate, severe or profound in severity. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect intellectual ability. A specific age limit is not used to define older people because adults with learning disabilities typically experience age-related difficulties at different ages, and at a younger age than the general population. This is reflected in the guideline title 'people growing older with learning disabilities'. Within the recommendations, this long form is used at the beginning of each section but in subsequent recommendations 'people' or 'people with learning disabilities' is used as a short hand. In all cases, the intended population is 'people growing older with learning disabilities'.

Glossary

Annual health checks

(an NHS initiative for adults and young people aged 14 and over with learning disabilities to provide health support and help identify health conditions that could otherwise go undetected)

Diagnostic overshadowing

(the tendency to attribute all behavioural, emotional, physical and social issues to a person's learning disability or a pre-existing condition while overlooking the possibility that they could be symptoms of other conditions or difficulties – an example would be attributing challenging behaviour to a learning disability when it could be a reaction to abdominal pain, which in turn might be symptomatic of a physical health problem)

Family members, carers

(includes people who are related to the person with a learning disability and anyone else who helps to provide informal support, for example friends; it does not cover staff who are paid to provide care or support)

Health action plan

(a personal plan for people with learning disabilities about how to stay healthy; it should detail what help and support they need to look after their health – this might include support to manage physical or mental health conditions, or actions in relation to lifestyle issues such as diet and exercise)

Hospital passport

(a hospital passport is designed to give hospital staff useful information that is not limited to illness and health; for example, it could include details about what the person likes and dislikes, in terms of physical contact or food and drink – the idea is to help hospital staff understand how to make the person feel comfortable)

Practitioners

(in these recommendations, 'practitioner' is used to mean a health or social care practitioner who provides care and support for older people with learning disabilities)

Sources

Hearing loss in adults: assessment and management (2018) NICE guideline NG98

Care and support of people growing older with learning disabilities (2018) NICE guideline NG96

Your responsibility

Guidelines

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Technology appraisals

The recommendations in this interactive flowchart represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, health professionals are expected to take these recommendations fully into account, alongside the individual needs, preferences and values of their patients. The application of the recommendations in this interactive flowchart is at the discretion of health professionals and their individual patients and do not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Commissioners and/or providers have a responsibility to provide the funding required to enable the recommendations to be applied when individual health professionals and their patients wish to use it, in accordance with the NHS Constitution. They should do so in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Medical technologies guidance, diagnostics guidance and interventional procedures guidance

The recommendations in this interactive flowchart represent the view of NICE, arrived at after

careful consideration of the evidence available. When exercising their judgement, healthcare professionals are expected to take these recommendations fully into account. However, the interactive flowchart does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

Commissioners and/or providers have a responsibility to implement the recommendations, in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity, and foster good relations. Nothing in this interactive flowchart should be interpreted in a way that would be inconsistent with compliance with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.