NHS
Greater Glasgow and Clyde

# Learning Disability Reviews: Raising the awareness

A practitioners guide to

NHS Greater Glasgow and Clyde
Learning Disability Review and Services.

# Introduction

This guide introduces the components of the NHS Greater Glasgow and Clyde template for learning disability health reviews. You may already have a detailed knowledge of many of the template components. The information included here aims to help you feel confident about delivering the consultation process as a whole.

**Three approaches underpin the consultation:**

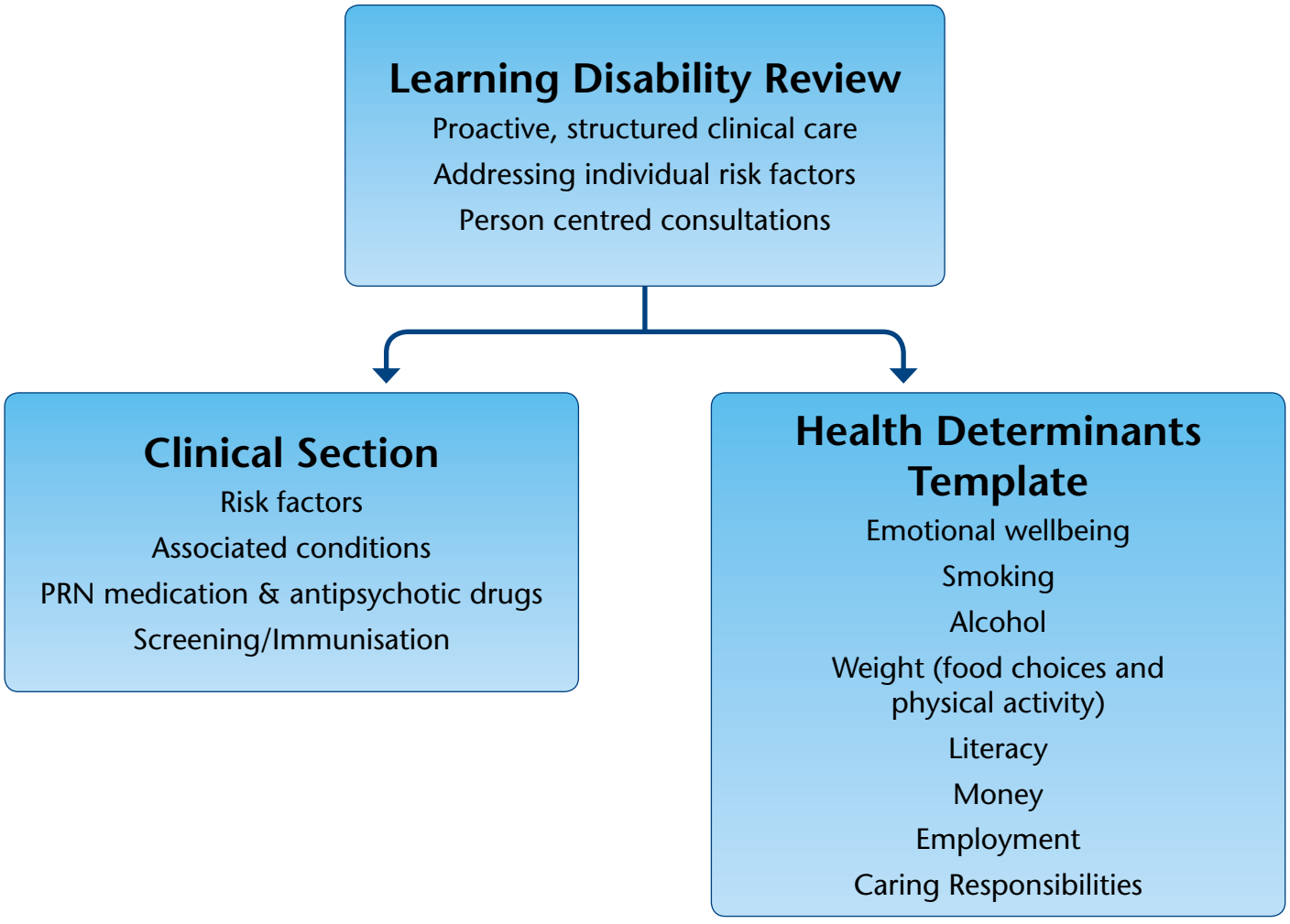
- Proactive, structured clinical care.
- Addressing individual risk factors.
- Person centred consultations.

The template has been designed in consultation with practice staff.

Research shows that regular health checks for people with learning disabilities can often uncover treatable health conditions, most of which can be simple to treat and make the person feel better.

- Improves the processes of clinical care.
- Ensures that evidence-based interventions are delivered, in keeping with guidelines and best practice.

Learning Disabilities: Annual Health Checks – **RCGP GUIDELINES**



# PERSON CENTRED CONSULTATIONS

Person-centred care means providing care that supports individuals to achieve the level of health that gives them the best opportunity to lead the life that they want. It involves supporting self management, sharing decision making and taking a collaborative approach to care and support planning.

Supporting self-management helps people to develop the knowledge, confidence and skills they need to make the best decisions and actions for them.

Person centred consultations are a major determinant of the outcomes of the interactions between clinicians and patients.

**A person centred consultation:**

- Fits with a patient's expectation of the consultation and information needs.
- Establishes what matters to the individual.
- Facilitates an agreed management plan.

There is evidence to show that person centred consultations:

- Improve patient satisfaction.
- Improve professional fulfillment.
- Save time.
- Increase compliance with therapy.
- Improve goal setting and action planning.

## LINKS

Information on inequalities sensitive practice as part of person centred care can be found **here**

## USING TEMPLATES TO ENHANCE THE PRACTITIONER-PATIENT RELATIONSHIP

Building a good relationship is considered by both patients and practitioners to be one of the most important aspects of care. Using computer-based templates ineffectively during a consultation can potentially interrupt the conversation. There is however emerging evidence to show how computers can be used to enhance the patient/practitioner relationship.

Computers allow you to share information with patients in a way that has not been possible in the past. Patients may signal how they prefer the computer to be used. For example, those who look at the computer while a practitioner is using it may be interested in seeing more. A response to this is to turn the screen to involve them in recording data and seeing the consultation process. Some patients will ignore the screen completely and focus on the practitioner. Don't attempt to involve a patient with the screen if they don't tend to look at it. What is important is to include your patient in the decision as to whether they wish to use the computer.

Another way of maintaining the relationship whilst inputting data is to think aloud, i.e. describe to the patient what you are doing while you are doing it. Some patients will introduce a new topic of discussion or ask questions while you are inputting data to the computer. Recognise this as an opportunity for them to do so and be aware they may introduce important information.

## The basics of the Learning Disability Review

Structured reviews significantly improve care for individuals with learning disabilities. The benefits of providing these reviews include:

1. Evidence-based delivery of biomedical care interventions.
2. The right type of delivery systems, care models and organisational approach.

**Important components of these delivery systems include:**

- Structured multidisciplinary team care.
- Integrated decision support.
- Use of electronic templates and other supportive information technology.
- Education and support to patients.
- Use of registers.

Electronic templates are therefore a vital element of effective care planning. They have been designed to support you to deliver a high quality, person centred care review. Templates can help you make decisions in conjunction with individuals, families and carers and take the right actions in improving their care. They are not intended simply as a way of recording information, although sometimes structured information is helpful to you in supporting the individual.

The content of the electronic template has been designed in partnership with NHSGG&Cs Learning Disability Liaison Team. This ensures the template contains the right information and high quality evidence to inform the care of your patient in accordance with local guidelines. The template can help you deliver consistent, clear and appropriate clinical care by providing a framework to enable flexibility to respond to each individual patient's needs.

*The electronic templates will be pre-populated with information from previous consultations, particularly around diagnosis.*

## Pre-consultation - language, communication and access support

### INTENTION

Identify any additional communication and/or access support needs to facilitate the consultation.

### TEMPLATE CONTENT

Hearing and vision

Physical and mental disability

Literacy

### WHY?

- In NHSGGC there are 41,400 people who have severe sight loss. One in eight people over 75 and one in three people over 90 years of age have serious sight loss. People with a learning disability are ten times more likely to have serious sight problems and this will be much higher for people with severe or profound learning disabilities.
- In NHSGGC approximately 13,000 people have severe to profound deafness. Within this group at least 1,400 people use British Sign Language, however it may be as high as 3,000. There is thought to be approximately 1,000 deaf blind people. People with learning disabilities are more likely to experience hearing loss. This can have a profound impact on how they are understood and how they are able to interact with others. Someone with communication problems and a learning disability might demonstrate challenging behaviours if they are unable to communicate a hidden or undiagnosed sensory loss.
- There are over 80 different languages spoken in Glasgow and NHSGGC has an in-house interpreting service which provides interpreters to NHS patients on request at any time day or night, 7 days a week.
- Compared to other Scottish cities, Glasgow has the highest level of reported disability among working age adults (24%). Recent research has shown that difficulty getting into surgery buildings was more likely among physically disabled patients, with a stronger association among disabled patients aged 65-84 years. Therefore ensuring accessibility is an important part of pre-consultation preparation. **More information**

### GOOD PRACTICE

- Meeting access needs can include physical access, communication support and accessible information. Meeting people's access needs contributes to meeting legal requirements for equalities legislation and improving person centred care.

### LINKS

NHSGG&C Interpreting Service and Accessible Information **Equalities in Health** the service also provides: British Sign Language and Makaton Interpreters

- Equalities **Evidence Review**
- **Communication Aid**
- **Easy Health**

## CONSENT

Patients have the right to know how their information is being used for the purposes of their clinical care and, when relevant, for secondary uses such as service planning, evaluation or research. If patients wish to opt out of data sharing, the template allows this to be recorded (our experience suggests that very few patients opt out).

### Links

Confidentiality Easy Read Booklet
Easy read guardianship
Welfare Guardianship
Adults with Incapacity
NHS_SPIRE Easy read leaflet

## PATIENT PREPARATION

Providing people with an opportunity to prepare can help to ensure they get as much as they can from their annual review. It means that they are in a much better position to contribute fully to the discussions and decisions made. An 'It's okay to Ask' leaflet can help people take some simple steps to get the most of their appointments. It can be ordered directly from NHSGG&C Public Health Resource Directory.

Individuals with a learning disability may require a few visits to the practice to become comfortable and confident with their surroundings and the review.

### LINKS

Easy Read Patient Letter.doc
Patient Health Check - Letter.doc
It's ok to ask leaflet.pdf
Public Health Resource Directory
Health and Wellbeing Directory

# 1. INTRODUCTION

**Severity and Cause of Learning Disability -**

Assessing a person's range of skills provides a more useful way of working out the extra support they require and identifying goals for further learning and training. There are thousands of different causes of learning disabilities. Specific causes of learning disabilities can have associated phenotypes including specific physical and mental ill-health e.g.

- Prader-Willi syndrome and affective psychosis.
- Down Syndrome and Dementia and Hypothyroidism.
- Tuberous Sclerosis and Epilepsy.

**Living and Support Arrangements –**

People with learning disabilities can live either with their family who are family carers, in rented accommodation with support from paid carers, or can live independently with minimal or no support. It is also important to note that not all paid care staff will have good knowledge of an individual. It is good practice to request familiar carers to attend the Learning Disability Health Review.

**Welfare Guardianship –**

By law, if an adult is unable to make a safe decision about his or her own welfare, a court can appoint someone else to make decisions for them.

This person is known as a welfare guardian. Welfare guardians can be a partner, carer, relative or social worker.

**Welfare Guardianship**

**Easy Read Welfare Guardianship.pdf**

**Adults with Incapacity –**

Part V of the Act relates to medical treatment. Adults assessed as incapable of making decisions concerning specific medical treatment/investigations should have a Certificate of Incapacity under Section 47 and treatment plan put in place. **Adults with incapacity Certificate.pdf**

**Language and Communication**

Communication difficulties are prevalent amongst persons with learning disabilities. Limited communication ability affects access to healthcare:

- To read and understand appointment letters.
- To convey information effectively to health staff.
- To fully understand recommendations and guidelines given by health staff.

People with communication difficulties can present as uncooperative, exhibit challenging behaviour and can be vulnerable and socially isolated.

Indicators may include:

- The person repeats back what is said by others.
- The person always talks about a favorite topic/says the same thing repeatedly.
- The person answers "yes" to everything.
- The person answers "no" to everything.
- The person answers "don't know" to everything.
- When offered a choice, the person always chooses the last option.
- The person is easily distracted, maybe walking away during conversation.
- The person is a "loner" and doesn't want to join in.
- The person changes topic in the middle of a conversation.
- The person does not use words.

**Sensory Impairments**

- There is an increased prevalence of sensory impairments within the learning disabilities population.
- It has been demonstrated that visual and hearing impairments are frequently unrecognised and under reported.
- People with limited verbal communication skills may have difficulty in conveying deterioration in hearing or vision and be unable to know of any benefit from improvement. This can have a profound impact on how they are understood and their ability to interact with others.

It is good practice therefore to assess vision and hearing in persons with a learning disability.

# ADDRESSING INDIVIDUALS RISKS/HEALTH NEEDS

## Intention

To identify characteristics or other conditions that place people in a different risk category for developing other long term conditions and/or complications.

Compared with the general population, people with learning disabilities have:

- Higher levels of health needs.
- More health needs that are unrecognised and unaddressed.
- More health needs that are sub-optimally managed.
- A different pattern of health needs.
- Lower life expectancy.
- Barriers in accessing and using health services.
- Greater disadvantages when services are reactive rather than proactive.

## Different pattern of health needs

Some problem behaviours e.g. self injury and pica, are fairly specific to learning disabilities and may be associated with specific genetic syndromes.

Most common newly identified health needs, following a health check are (please note however that problems are detected across the full range of bodily systems):

- Impacted cerumen.
- Gastro-oesophageal reflux disorder.
- Mental ill-health.
- Obesity.
- Xerosis cutis.
- Visual impairment.
- Constipation.
- Tinea.

## Prevalence of Health Needs

| Increased Prevalence | Decreased Prevalence |
|---|---|
| **Risk of choking** | Health problems related to smoking |
| **Epilepsy** | Health problems related to alcohol |
| **Gastro-oesophageal** | Health problems related to the use of illegal drugs |
| **Reflux disorder** | |
| **Constipation** | |
| **Sensory impairments** | |
| **Osteoporosis** | |
| **Schizophrenia** | |
| **Dementia** | |
| **Bipolar disorder** | |
| **Dysphagia** | |
| **Dental disease** | |
| **Musculoskeletal problems** | |
| **Accidents and falls** | |
| **Nutritional problems** | |

## Specific Screening needed for individuals

Down syndrome - People with Down syndrome on the whole do not have medical problems that differ from those in the general population. However some medical conditions are overrepresented. These conditions include: Cardiac disease, Thyroid disorder, Hearing impairment, Ophthalmic problems and early onset Dementia.

**Fragile X Syndrome** – is a genetic condition that causes learning disabilities. It can occur in both genders but males are more frequently affected than females and normally with greater severity. Fragile X Syndrome can cause a wide range of difficulties with learning, as well as social, language, emotional and behavioural problems.

**Tuberous Sclerosis** – is a genetic condition that can lead to growths in various organs of the body. Those most commonly affected are the brain, eyes, heart, kidneys, skin and lungs. These growths are sometimes referred to as benign tumours. Tuberous Sclerosis can cause a number of conditions including learning disabilities, epilepsy and behavioural difficulties.

**Prader-Willi Syndrome** – is a genetic condition which causes over-eating and can cause death before the age of 30, as a result of complications arising from morbid obesity.

- Total control of own finances means in most cases that money will be spent on food therefore household bills (for those in supported living) may remain unpaid.
- Inability to recognise/report internal injury or disease because of high pain threshold. More likely to trip or fall due to poor balance and coordination. Some obsessive activities (e.g. extremely heavy smoking, skin-picking, drinking liquids to excess) are a serious threat to health or may involve the person in preventable risk. Underdeveloped social skills and immature emotional development can lead to misunderstanding and isolation.
- Possibility of developing mental health problems – any marked change in a person's behavior or general mental well-being needs to be assessed.

## Ethnicity

## Co morbidities (rheumatoid arthritis, hypertension, mental health and chronic kidney disease)

## WHY

- Ethnic health inequalities vary by gender, with women's health poorer than men's and are significantly greater in older age-groups. Poor health is caused by a wide range of factors, including biological determinants (age, sex, hereditary factors) and wider social determinants such as education, social position, income, local environment, and experiences of racism and racial discrimination. The social determinants of health are unequally distributed across ethnic groups, leading to unjust and preventable health inequalities. **Further Information**
- Type 2 diabetes is more common in people from some ethnic groups including people with African, Asian and Caribbean backgrounds, compared with European populations. Due to the higher risk of diabetes and other health conditions NICE have recommended that practitioners are made aware and make their patients aware that members of black, Asian and other minority ethnic groups face an increased risk of chronic health conditions at a lower BMI than the white population (below BMI 25 kg/m2). **Further Information**
- The relationship between COPD and ethnicity is complex. Poorer access to primary care in ethnic minorities might lead to later presentation with respiratory symptoms and later diagnosis with more severe disease. **Further Information**
- Rheumatoid arthritis is a chronic disabling disease associated with an increased risk of cardiovascular disease, low mood and depression. It may also worsen the effect of other long term conditions. Finally, it is a powerful independent risk factor for increased mortality from cardiovascular disease.
- Hypertension is an important risk factor for disease progression.
- World reductions in both developments of complications of diabetes and recurrent vascular events in stroke and coronary health disease.
- Around 30% of all people with a long term condition also have a mental health problem, especially those who have multiple long term conditions. The combination of mental health problems with other long term conditions has serious implications including:
  - Poorer clinical outcomes.
  - Lower quality of life.

In both coronary heart disease and diabetes there is also evidence of earlier death in patients with co-morbid mental health conditions. It is important to detect (and even more important to manage effectively) mental health problems as part of the chronic disease management process.  About 30% of people with learning disabilities have mental ill-health at any one time.

- Chronic kidney disease often co-exists with diabetes and hypertension. Co-morbidities require good coordination of all aspects of care to help manage often complex co morbidities, optimise medication, monitor and respond to laboratory parameters to minimise the risk of disease progression.
- Reduced ability to manage their condition effectively.

## GOOD PRACTICE

- Clinicians should review this section in advance of their consultation and consider modifying their approach in the light of these characteristics.
- Book interpreters well in advance of consultation.
- Understanding of Cultural issues which may impact on self -management.

## LINKS

- Ethnicity coding guide
- Interpreter **booking information**

# 3. ASSOCIATED CONDITIONS

Although multi-morbidity is common for individuals with a learning disability, the pattern of health needs can differ from the general population. As well as completing the relevant Long Term Condition Review, please also consider the following:

- Risk of Choking/Aspiration
- Reflux disorder
- Constipation
- Osteoporosis
- Muscle contracture
- Wheel chair aids
- Mental ill health
- Problem behaviours
- Autism
- Epilepsy
- Falls or accidents
- Co-ordination
- Mobility
- Pain

# 4. MEDICATION COMPLIANCE

## Intention

To discuss the importance of medication adherence in order to reduce the risk of disease progression, improve the patient's wellbeing and help them to live independently.

## Template content

- Prescription
- Compliance
- PRN

## Why

- Patients on antipsychotics require annual FBC, U&Es, LFTs, fasting glucose and prolactin.
- PRN medication is given when an individual to be treated has a reduced ability to communicate and may lack capacity to recognize when medication may be of benefit. It is good practice for protocols to be put in place for people receiving PRN medications, in particular for such things as pain relief, behaviour management and bowel management. Additionally it enables such treatments to be delivered safely and appropriately by carers.
- PRN Protocol
- PRN Protocol Guidance
- Patients on Haloperidol, Pimozide and Thioridazine require an annual Electrocardiogram (ECG).
- Patients who suffer from cardiac problems and are on antipsychotics require an annual Electrocardiogram (ECG).

## Good Practice

- Is liaison with Learning Disability Services/Psychiatry beneficial for an update?
- Is the patient education up to date?
- Is the patient education material sufficiently clear to them?
- Is there a polypharmacy issue we can address?
- Is the patient receiving support to manage side effects?
- Can prescribing changes be made to minimize these problems?

# 5. SCREENING

- Health screening programmes for the whole population across Scotland have consistently been shown to be poorly accessed by people with learning disabilities.
- **Bowel Cancer:** is likely more common in people with learning disabilities; poor diet may be contributory factor. Information can be inaccessible and people may not have the support to help them complete the bowel testing kit.
- Bowel screening test
- Bowel Screening information for carers

- **Breast Screening:** Breast awareness measures are likely lower, and may pass unnoticed, due to a lack of education, accessible health education/information, inaccessibility of services and fear.
- "A guide to breast screening"
- Breast screening 'Helping you decide' booklet

- **Cervical Cytology:** Some women with learning disabilities are sexually active through choice and others are unknown survivors of abuse. Easy read information is available from the links below;
- A guide to having a smear test.pdf

- **Abdominal Aortic Aneurism Screening:** Screening is for all men aged 65 years or over
- Abdominal Aortic Aneurysm screening booklet

# 6. IMMUNISATION

## Intention

To protect patients with a learning disability and other long term conditions who are most at risk of developing serious complications should they develop influenza and Hepatitis B.

## Template content

- Flu Immunisation
- Hepatitis B

## Why

- **Flu Immunisation.** Patients with Long Term Conditions after adjustment for age are at 6 to 19 fold increased risk of dying following influenza infection, dependent on their underlying condition.

  Influenza is a simple and cost effective preventive intervention. It should be offered to all patients in clinical risk groups at higher risk of influenza associated morbidity and mortality. The flu immunisation is recommended for people with learning disabilities, especially for persons in the **high risk categories** - cerebral palsy, profound learning disabilities, living in residential homes, nursing homes, long-stay NHS hospital, supported group living and/or attending a day centre, having chronic respiratory disease (including asthma), chronic heart disease, chronic renal disease, chronic liver disease, immunosuppressant, diabetes, or aged 65 years or over.
- **Hepatitis B.** A higher prevalence of chronic Hepatitis B infection has been found among individuals with learning disabilities in residential accommodation than in the general population. Close, daily living contact and the possibility of behavioural problems may lead to residents being at increased risk of infection. Vaccination is therefore recommended. Similar considerations may apply to children and adults in day care, schools and centre's for those with severe learning disabilities. Decisions on immunisation should be made on the basis of a local risk assessment. In settings where the individual's behaviour is likely to lead to significant exposure (e.g. biting or being bitten) on a regular basis, immunisation should be offered to individuals even in the absence of documented hepatitis B transmission.

# 7. CLINICAL EXAMINATION

## Intention

To identify any unmet health conditions or any complications or risk factors for progression on an existing health condition, which you can discuss with you patient and thereby improve their outcomes.

## Template content

- Dental check
- Hearing check
- Impacted cerumen
- Vision check
- Height/weight/BMI
- Foot check
- Stoma care

### Dental check –

Persons with learning disabilities have high levels of unmet oral health needs. One in three people with learning disabilities have unhealthy teeth and gums; this can increase to four out of five for adults with Downs's syndrome. This includes gum disease, untreated dental caries and missing teeth. G.O.R.D, anticholinergic drugs and co-occurring health conditions contribute to dental erosions.

### Hearing Check –

Compared with the general population, hearing impairments are more common in people with a learning disability: approximately 30% have a hearing impairment. They can be congenital or acquired later in life. Sensory impairments are much more likely to be unrecognised and paid carers in particular under-report sensory impairment. Many learning disability syndromes have specific association's e.g. sensorineural damage, structural abnormalities of the inner ear. Down syndrome, mitochondrial disorders, and congenital rubella are especially associated with sensory impairments. Age-related impairments occur earlier in persons with Down syndrome. Many can't self-report age-related hearing impairments. Hearing can be assessed even in persons with the most profound learning disabilities.

### Impacted Cerumen –

Impacted ear wax is common in this population. Congenital structural anomalies in the ear and ear-poking behaviours contribute. This can cause/exacerbate hearing impairment. Many persons with learning disabilities cannot communicate this additional disability.

### Vision check -

People with learning disabilities are 10 times more likely to have sight loss. 6 out of 10 people with a learning disability will need glasses (the more severe the learning disability the more likely they are to have sight loss). Sight loss is often hidden as

people are unable to understand or communicate that they are having problems.

**Does the person have difficulty with the following?**

- Recognising faces?
- Reading facial expressions?
- Being in bright light or low light?
- Hesitancy at steps, stairs or with change in colour and texture of flooring or walls?
- Bumping into things?
- Finding things? Navigating unfamiliar surroundings?
- Reading?
- Participating in usual hobbies?

### Height/Weight/BMI –

### Why-

Obesity worsens the clinical impact of existing chronic diseases

### Good Practice –

- For accurate height measurement: use a wall-mounted measuring device, consisting of a vertical ruler with a sliding horizontal rod adjusted to sit on top of the head. The patient should be standing upright on a firm surface, looking straight ahead, arms at their sides with shoes removed and feet together. The shoulders, buttocks and heels should be touching the wall. Height should be recorded in centimeters.
- Weight measurement: Scales need to be calibrated twice a year according to the manufacturer's recommendations. Patients should remove shoes, heavy outer clothing and items from their pockets. Weight should be measured and recorded in kilograms.
- Some Practices may not have the equipment to weigh individuals who are wheel chair users (In order to use this equipment you must first be trained to do so). Therefore it is important to ask the individual/carer if they are able to get their weight checked at another service such as day care centres, before attending their appointment. In cases where this service is unavailable to them, the Practice Nurse should contact their local learning disability team. A MUST score should be completed and a referral made to the dietician service regarding concerns of weight lost.
- BMI is calculated with the formula: Weight (kilograms)/height (metres2).
- If patient has a BMI <18.5 and/or experiencing unexplained weight loss, regardless of BMI, carry out nutritional screening using MUST tool.
- MUST tool: a five-step screening tool to identify adults who are malnourished or at risk of malnutrition. The tool includes management guidelines which can be used to develop a care plan.

**Links to 'Keep yourself healthy leaflets' –**

- Being Overweight
- Choosing what you Eat and Drink
- Planning your Meals
- Staying fit and Healthy

**Foot Check -….**

**Foot Check** – Advice and support can be given to people with learning disabilities, their families or carers regarding personal footcare. This includes checking that the person's feet are in good condition, providing advice on personal hygiene and skin care. Advising on length and condition of toenails and referring to podiatry or the GP if needed.

**Stoma Check** – It is good practice to look at a patients Stoma sight to make sure there are no signs of infection. If the sight is red, inflamed, and granulation or anything protruding from the sight it would be good to get the GP to check things over. The GP may also want to refer the person on to their Stoma Clinic.

# 8. MENTAL HEALTH

## Intention

Identify the possible presence and severity of mental health issues.

About 40% of people with learning disabilities have mental ill-health at any one time.

- It is frequently overlooked by carers, causing unnecessary suffering.
- Presentation of Mental Health can differ in people with learning disabilities and this can increase with severity of learning disability.
- Onset of problem behaviours can indicate mental ill-health.
- Reluctance to engage with previous activities, odd behaviours, or withdrawal may be signs of mental ill-health.
- Sometimes symptoms are dismissed as being due to a change in a person's support package – this is unwise, as life events such as this can trigger mental ill-health in this population and treatment may be indicated.

## Problem Behaviours

- About 20% of people with learning disabilities have problem behaviours at any one time.
- Onset of problem behaviours can indicate mental ill-health or poor physical health. This requires physical health investigation first to rule out a physical health cause to avoid diagnostic overshadowing.
- Where there is no underlying physical or mental ill-health to account for the problem behaviours they require treatment in their own right.
- Antipsychotic medication should NOT be used as a first line approach. It is not often effective and causes side effects.
- There are a range of interventions that can be beneficial. This almost always requires referral to the specialist learning disabilities team.
- There is a dedicated learning disabilities psychiatric service across all parts of Greater Glasgow and Clyde. There are also psychologists, nurses, occupational therapists, physiotherapists and speech and language therapists that specialize in working with people with learning disabilities.
- If known to Learning Disability Services liaise with the Learning Disability team highlighting the health review.

# 9. COMPLETING THE INTERVIEW

Is your patient living with a long term condition? At the end of the interview you will be prompted to complete any other relevant Long Term Condition reviews.

### Why

- When done well annual review significantly reduces the risk of mortality, disease progression and recurrent vascular events.

### Good practice

- Review recent trends in measurements and risk factors with the patient.
- Discuss potential explanations for the findings of routine monitoring (either favourable or not) from both the patient's perspective and from your own.
- Consider options for change/improvement in partnership with the patient.

### Emergency Care Summary and Key Information Summary (KIS)

People with learning disabilities have differing health needs and have earlier mortality rates and often communicate their needs differently. The completion of a key information summary for all those on the Learning Disability register ensures services are better informed to deal with an individual's specific health needs, aiming to reduce the delay in access, treatment and diagnosis.

KIS should include the following:

- Severity and cause of learning disability where known (or state unknown).
- Living and support arrangements.
- Next of Kin details where applicable.
- Adults with Incapacity status (section 47 if issued).
- Details of communication difficulties if known.
- Details of additional medical need which may place the patient in danger e.g. high risk aspiration.

# HEALTH DETERMINANTS

Having a conversation with patients about their lifestyle and life circumstances is core to supporting the management of long term conditions successfully. The health determinants (HD) section is designed to help facilitate this conversation by identifying issues potentially affecting the patient's health and wellbeing.

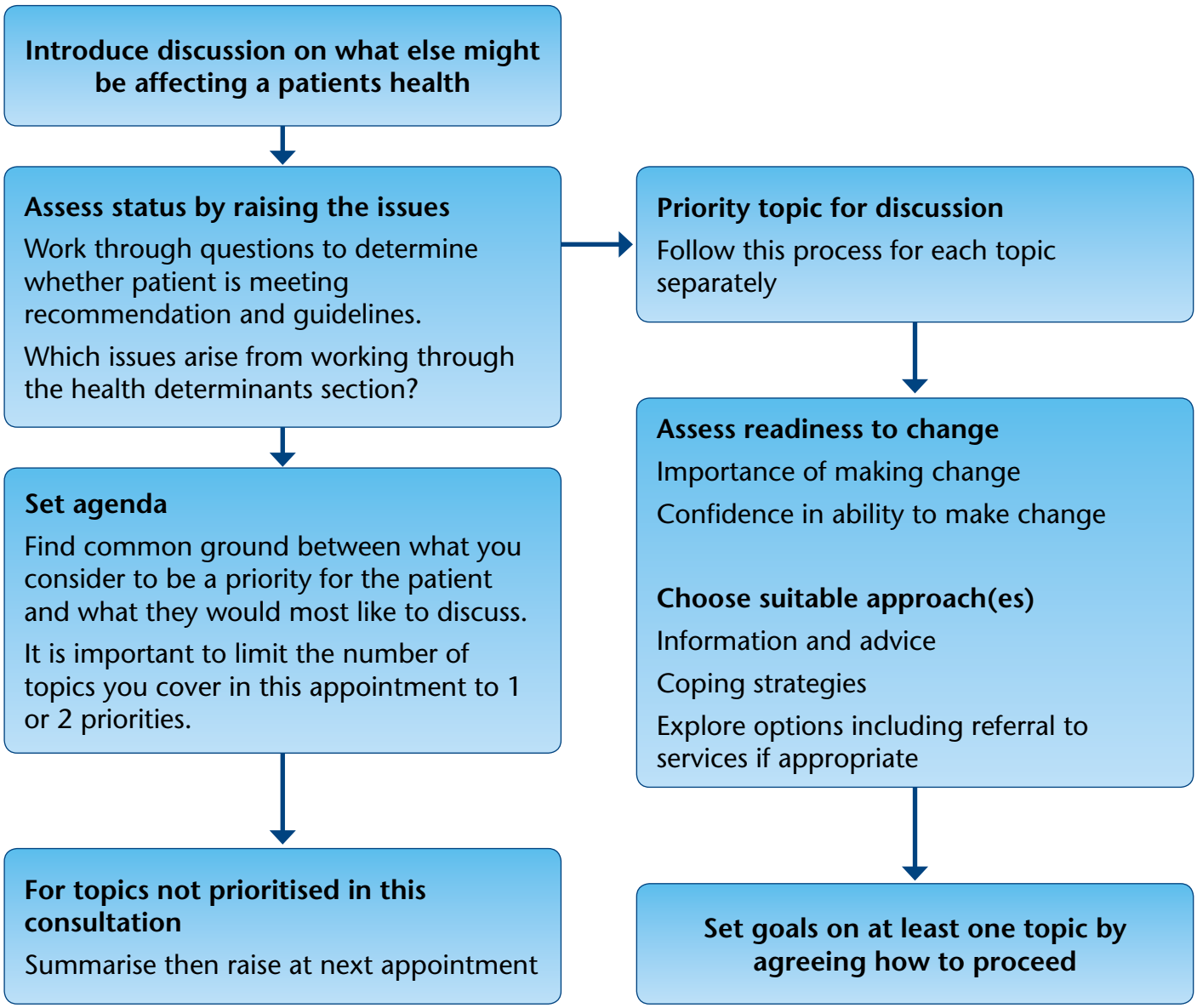
By assessing status, you can identify health behaviours and wider issues which may be impacting on or affecting the patient's ability to manage their long term condition (support services are linked to each status).

By setting an agenda, you will have the time to find common ground between what you consider to be important issues and what your patient would like to discuss further.

## HEALTH LITERACY

Adapting how you communicate with people can help everyone, not only those with low health literacy. There are several evidence-based health literacy interventions that can help:

- Avoid jargon and use language that is easy for the patient to understand, both when you speak to them and in any written information you provide.
- Limit information (3 to 5 key points).
- Check that you have explained everything in ways people understand by asking them to explain in their own words the information you have given. For example, you might say 'I want to make sure that I have explained your medicine clearly. Can you tell me how you will take your medicine?'.
- Check confidence for following agreed treatment/activities. For example you might say 'On a scale of one to ten, how confident do you feel about doing what we have discussed?'.
- Provide written or other forms of information covered in the consultation, such as leaflets – providing they are easy to understand.



Making a brief intervention means adopting an evidence-based approach to addressing lifestyle issues. It provides you with alternative and sensitive strategies to support your patients to make changes. Practice nurses are recognised as being skilled in supporting self-management. The brief intervention involves patients as partners in managing their own health. We know patients respond well to 'supported' self management.

## HEALTH & WELLBEING SERVICE DIRECTORY

The Health & Wellbeing Service Directory (http://www.nhsggc.org.uk/infodir) lists community services to support patients to tackle issues arising from this discussion.

## NOTE ON EMOTIONAL WELLBEING

The following pages list the topics in the HD section. Emotional wellbeing can be addressed as part of agenda setting. Information on this topic is contained in The Basics of CDM (see page 11).

### Assess Status Section

By working your way through the questions in this section of the template you can determine issues which may be having an impact on the person's ability to manage their condition.

### How to start the conversation

It is helpful if you consider in advance how to move from the clinical to the non-clinical part of the consultation.

Here are some examples of ways to start the conversation: "I have a few questions to ask about different things which can affect your health/condition. Are you happy to spend the next X minutes discussing these a bit further?"

*"We have found that many people who have condition X have benefited from making small changes to their lifestyle. Would you be willing to look at these issues in a bit more detail?"*

### Setting the Agenda

Based on the responses your patient has given in the "Assess Status" part of the consultation you will have an overview of the issues which may be affecting their health and well-being.

Find common ground between what you consider to be a priority and what your patient would most like to discuss. This allows you to acknowledge your clinical responsibility while still maintaining a person-centred approach.

It is important in this section to be open and honest about your position in relation to the issues highlighted.

You may wish to consider offering the patient an opportunity to highlight areas of concern first before you discuss any other relevant issues.

### Highlight the areas for potential discussion

Ask permission to give the patient feedback on how any of the issues identified relate to their individual circumstances.

A degree of sensitivity is required and the practitioner must endeavour to be supportive and non-judgemental.

Invite the patient to identify other potential issues which may be more pressing.

Here is an example of a way to start this section of the consultation:

*"Following a heart attack, we know that there are lots of different things that can impact on your recovery and reduce the chances of another incident. These include the tablets you take, smoking, weight, physical activity, healthy eating and alcohol. From a health perspective we know that quitting smoking is one of the most important things to do following a heart attack but I wonder if there is anything on this list which you might like to talk about today – anything you might like to talk about changing or getting more information about?"*

Plan how to use the remaining time to explore the issue further.

Emphasise personal responsibility.

### Goal Setting

### OUTCOMES OF THE CONVERSATION

Remember this part of the consultation is not all about referring to services it is about working with the patient to identify relevant goals:

"I will stop smoking by next June" or "I will think about stopping smoking by next June" or "I will try my best to smoke less" etc.

### Patient not ready to change

Conversations to support change may last for many years. It is perfectly reasonable to suggest to the patient that they may not be ready to make changes, but they may wish to consider doing something and perhaps they might want to talk about it next year.

The practitioner's key role is to ensure this decision is informed and thoughtful

A useful final question could be:

"What would need to happen for you to reconsider change?"

Reflecting on the answer can help the patient to really hear what it is they are saying and to check they are comfortable with the decision.

Agreeing to discuss this issue further at another time is an acceptable goal.

### Patient still unsure

The practitioner's role is to support the patient to reflect on the issues discussed.

The decisional balance tool can help to distil the issues surrounding change and taking it home may generate more clarity.

Offering the patient information may also help.

## Patient ready to change

Support the patient to generate ideas.

If they need help offer a menu of options.

Please consult the **Health and Wellbeing Directory** for local service details.

Exchange information on the process of making change e.g. experiences of others making changes, realistic expectations

Considerations for setting goals:

- Complexity of need.
- Number of behaviours that patient may need to address.
- Prioritisation.
- Making a SMART plan.

If the patient is already meeting the recommendations or has no issues, reinforcing maintenance is an important aspect of supporting long term change and preventing relapse.

## Smoking

### INTENTION

To motivate a quit attempt.

### TEMPLATE CONTENT

- Ask patient if they smoke
- Record status
- Number of cigarettes per day
- Advise them to stop

### WHY

- Smoking substantially increases the risk of developing heart disease, lung cancer, COPD, strokes, stomach ulcers, stomach cancer, bladder cancer, oral cancer among many others.
- Stopping smoking is the only proven way to reduce the rate of decline in lung function in people with COPD.
- A person smoking 20 cigarettes a day has six times the risk of stroke compared to a non-smoker. Within two years of stopping smoking, a former smoker's risk of stroke is reduced to that of a non-smoker.
- Giving up smoking dramatically reduces the risk of a heart attack and is particularly important for those who have other risk factors such as high blood pressure, raised blood cholesterol levels and are diabetic or overweight and physically inactive.
- Light smokers are also at increased risk of CHD.
- If smokers are referred to specialist stop services by a GP practice, they are more likely to attend and to stop smoking.

### GOOD PRACTICE

- Explore what the patient understands about smoking and their condition.
- Regularly raising the topic of smoking and engaging in brief interventions is effective in triggering quit attempts and encouraging smokers to use the smoking cessation services.
- Some patients believe they may gain weight if they stop smoking. Concerns about weight gain should be addressed by health care providers whilst emphasising the fact that the health benefits of smoking cessation far outweigh post cessation weight gain, even in people who are focused on weight management.

## Alcohol

### INTENTION

To reduce harmful drinking.

### TEMPLATE CONTENT

- Ask patient if they drink
- Record status
- Number of weekly units

### WHY

- Brief interventions reduce alcohol consumption amongst hazardous drinkers in the order of 15-30% for up to one year.
- Alcohol-related deaths have almost doubled in the last decade. Mortality rates in Scotland are now twice that of the rest of the UK, with the rate among Scottish women now higher than that of English men.
- Harmful consequences of drinking are not confined to dependent drinkers. The wider population of people drinking at hazardous and harmful levels experience harm from their alcohol consumption; it is for this group whom brief interventions are most effective.

### GOOD PRACTICE

- Using the FAST (Fast Alcohol Screening Tool) screening tool at the assess status stage can help patient to identify the impact of their drinking and support them to prioritise it for further discussion.

## Weight

### INTENTION

To attain a healthy BMI through diet and physical activity.

### TEMPLATE CONTENT

- Wants to lose weight
- Patient initiated diet
- Exercise grading

### WHY

- Someone who is 40% overweight is twice as likely to die prematurely as a person within a healthy weight range.
- 47% of type 2 Diabetes can be attributed to obesity, 36% of hypertension, 18% of myocardial infarction, 15% of angina and 12% of osteoarthritis.
- Malnutrition affects 10% of adults at GP practice and 33% of patients admitted to hospitals and care homes.
- Increased physical activity can modify cardiovascular risk factors including blood lipids and resting blood pressure.

### GOOD PRACTICE

- If BMI >25 ask patient what aspects of their lifestyle they think are contributing to their weight.
- If patient has a BMI <18.5 and/or experiencing unintentional weight loss within the last 3-6 months, carry out nutritional screening using MUST.
- Increasing their activity levels as a means of losing weight, discuss what activities they have enjoyed in the past or new ones that might interest them. Provide physical activity information or signpost to local services.

## Literacy

### INTENTION

To facilitate access to adult education service where appropriate.

### TEMPLATE CONTENT

» Identify literacy and/or numeracy issues

### WHY

- People with literacy difficulties have poorer health status, are less likely to understand their long term condition, and are also less likely to adhere to prescribed courses of treatment.
- One person in 28 in Scotland faces serious challenges with literacy and/or numeracy.
- Older people are more likely than younger people to have literacy difficulties.
- People who live in the 15% most deprived areas in Scotland tend to have lower literacy scores.

### GOOD PRACTICE

- To identify if a patient is experiencing difficulties with literacy, ask: "How often do you need to have someone help you with understanding forms, letters, or medicine labels?"
- If person responds either "sometimes" or more often than sometimes, this is an indicator of some degree of difficulty with literacy and/or numeracy.

## Money

### INTENTION

To facilitate access to money advice service where appropriate.

### TEMPLATE CONTENT

» Identify money worries

## WHY

- Many people are currently experiencing changes to their welfare benefits which will impact on their ability to manage their finances.
- The tax and benefits system is complex and there is a lack of awareness of entitlement.
- Money advice services have a prevention role.
- Healthier Wealthier Children found an average of £3,000 per annum per family from raising the issue of finance.

## GOOD PRACTICE

- Ask patient if they are experiencing any money worries or debt problems.
- One way of doing this is to ask "How do you manage the bills?"
- Or let them know that people living with long term conditions might be entitled to more benefits after diagnosis.

## Employment

### INTENTION

To facilitate access to employment service where appropriate.

### TEMPLATE CONTENT

- Employment status
- Difficulties in workplace

## WHY

- For those with ongoing health conditions, remaining in work is shown to be beneficial to their health as it can help them recover from sickness and decrease the risk of long-term incapacity.

## GOOD PRACTICE

- In addition to helping those looking for jobs, the employment services are able to support someone who is unhappy at work and would like support to consider other options.
- Employment services can support people to access volunteering opportunities or further education courses.

## LINKS

- Local Social Work Services will be able to provide advice for individuals who have a learning disability.
- Please contact your local Social Work service via Sci gateway.

## Caring responsibilities

### INTENTION

To facilitate access to carer support where appropriate.

### TEMPLATE CONTENT

» Carer status

### WHY

- Around 10% of the population provide informal personal care to a relative, partner or another person.
- Compared with non-caregivers, caregivers have poorer mental and physical health. They often have substantial unmet support needs.
- The carer's wellbeing is affected by the situation of the person(s) they care for including lack of responsive and joined-up services.
- The largest proportion of households with a carer (28%), are in the 20% most deprived areas.

### GOOD PRACTICE

- Providing information and advice is important as part of a preventative approach to supporting carers and when someone is new to caring. It is also important as the nature or intensity of caring changes.
- A carer is defined as someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

# Further information and support

## 1. TRAINING OPTIONS

Learning tables have been developed to support the learning needs of practice nurses to deliver safe and effective care. The education opportunities that we are recommending are not only designed to underpin and support clinical excellence for your patients but will also provide active learning opportunities for professional regulation and NMC revalidation.

Learning tables can be accessed **www.staffnet.ggc.scot.nhs.uk/Partnerships/Greater%20Glasgow%20and%20Clyde%20Services/Primary%20Care%20Support/Practice%20Nurses/Pages/default.aspx** - Learning opportunities

## 2. LOCAL LEARNING DISABILITY TEAM

Local Learning Disability teams can be referred to via sci gateway or can be contacted for advice on the following link: **www.staffnet.ggc.scot.nhs.uk/Partnerships/Greater%20Glasgow%20and%20Clyde%20Services/Primary%20Care%20Support/Practice%20Nurses/Learning%20Disability%20booklet/Learning%20Disabilities%201.aspx?PageView=Shared**

## 3. SOCIAL WORK SERVICES

For referral to social work services please refer via Sci gateway.

## 4. PRACTICE NURSE Support and Development Team

The Practice Nurse Support and Development Team support workforce planning and development. As part of this, they can provide practice nurses with 1:1 mentoring, small group learning and telephone support. They also maintain the locum list.

**Phone:** **0141 211 3711**

**Email:** **PNATeam@ggc.scot.nhs.uk**

## Useful website

**www.staffnet.ggc.scot.nhs.uk/Partnerships/Greater%20Glasgow%20and%20Clyde%20Services/Primary%20Care%20Support/Practice%20Nurses/Learning%20Disability%20booklet/Learning%20Disabilities%201.aspx?PageView=Shared**

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