

## CHAPTER 20

### Physical Health in people with Intellectual disabilities

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*“There has been an acceptance in society, and even in the medical profession, that people with mental health problems and intellectual disability will live shorter lives and will suffer because of unmet health needs. In the vast majority of cases, there is no good reason for this. But the voice of these vulnerable groups often goes unheard, and the status quo remains unchallenged.”* Professor the Baroness Sheila Hollins.

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#### Introduction

People with intellectual disabilities have a shorter life expectancy and an increased mortality rate across all ages compared to the general population. The main contributors to the health inequalities experienced by people with intellectual disabilities include:

- (1) Social determinants such as poverty and unemployment;
- (2) Health problems related to intellectual disabilities (such as congenital abnormalities related to people with moderate to profound intellectual disabilities);
- (3) Limited communication and health literacy skills, which may reduce their capacity to understand and convey health needs effectively to others;
- (4) Personal health risks related to diet and sedentary lifestyle; and
- (5) Organisational barriers to accessing mainstream health care [1]

People with ID continue to experience poor healthcare and social care with life expectancy at birth nearly 20 years lower than the general population [2]. Potentially avoidable causes of death in people with ID include epilepsy (3.9% of deaths), aspiration pneumonitis (3.6%) and colorectal cancer (2.4%). Analysis showed that a higher proportion of deaths from causes amenable to good medical care but a lower proportion from preventable causes compared with people without ID [2]. The recent Confidential Inquiry into the deaths of people with a learning disability (CIPOLD), which reviewed the deaths of 247 people with ID, showed that they continue to die at a younger age from avoidable causes [3].

People with intellectual disabilities also experience higher levels of long-term conditions than the general population at a younger age. The burden of multi-morbidity is higher due to higher rates of some physical and mental health conditions and is common in all age groups in adults with ID. The pattern of disease also differs from the general population, for example, obesity affecting up to 38% of people with ID compared to 25% of the general population [4] (see Box 20.1).

Box 20.1: Common comorbidities in people with ID related to physical health

- Poor nutritional well-being:  
Underweight or overweight
- Gastro-oesophageal reflux
- Constipation
- Osteoporosis
- Visual and Hearing Impairment
- Musculoskeletal impairment

Additionally, the prevalence of multi-morbidity does not follow the typical gradient as seen in the general population across areas of increasing neighbourhood deprivation, importantly highlighting that services are equally needed in all areas. Cooper et al reviewed primary health-care data on 1,424,378 adults (18 years or over) registered with 314 representative Scottish practices, which included 8014 adults with ID [5]. The ID group was significantly more likely to have more health conditions, with the biggest difference found for epilepsy, constipation and visual impairment. Hearing loss, eczema, dyspepsia, thyroid disorders and Parkinson's disease or Parkinsonism were all more than twice as likely to be prevalent in those with ID compared to controls. Lower relative prevalence for the adults with ID was found for cardiovascular related conditions (coronary heart disease, peripheral vascular disease, hypertension, atrial fibrillation, any cancer over the last 5 years and chronic obstructive pulmonary disease (COPD)). Comorbidity increased with age but is highly prevalent at all ages, being similar at age 20-25 in those with ID to 50-54 year olds in the general population. Similarly, in older groups of people with ID, patterns of comorbidities do not follow those seen in the general population with again relatively low levels of cardiovascular disease and higher levels of neurological conditions [6].

Symptoms and signs related to brain dysfunction can be categorised into the following: 1) cognitive dysfunction, 2) neuromotor dysfunction, 3) impulsive behaviours and 4) seizures. Cognitive dysfunction is loss of intellectual functions such as thinking, remembering, and reasoning of sufficient severity to interfere with daily functioning. Neuromotor dysfunction, particularly extrapyramidal signs and symptoms (EPSS), plays an important role in the assessment and treatment of people in the early stages of psychotic disorders such as schizophrenia and the effect of psychotropic drugs. Impulsive behaviours such as physical violence, property destruction, trichotillomania and self-injurious behaviour can be common presentation as a sign of distress related to a physical illness particularly in those with limited communication [7]. Epilepsy is a common condition in people with ID, with prevalence as high as 26% as well as difficulty in seizure control and associated higher rates of behavioural and psychological problems [8]. Additionally, using psychotropic medication to manage neuromotor dysfunction may worsen seizures and conversely anti-seizure medication may worsen behaviour.

As a psychiatrist you may be required to undertake assessment of a patient with whom you are not familiar with. This may occur out of normal office hours such as the evening or a weekend when you have limited access to records and limited access to accurate information from regular care givers. With people with mild ID you may gain some history from the individuals themselves but for people with more profound cognitive impairment you'll have to rely on written information in care plans and clinical notes and those given to you by third parties such as paid care providers.

People with ID are especially prone to developing physical illness but because of communication difficulties, behavioural manifestations may be the presenting feature (see Figure 20.1). Additionally, clinicians may delay investigation or fail to appreciate symptoms by associating them with the ID, which can result in diagnostic overshadowing [9].

<insert figure 20.1>

**Figure 20.1: Symptoms and Signs related to common conditions in ID**

Identifying common sources of pain (such as ear infections, headaches, reflux oesophagitis, urinary tract infection and constipation) may be especially difficult. This can be challenging and there may be pressure and expectations from carers to prescribe

medication to possibly sedate the person with ID and or arrange an emergency alternative placement. It remains important at this time to perform a thorough mental health and physical examination as well as assessing mental capacity before making a significant intervention that could potentially worsen the situation.

It is now recognised that the identification of mental health and physical problems in people with ID may be difficult due to diagnostic overshadowing, with attribution of either the physical or mental health problem to the ID, and ‘normalising’ it can lead to unmet health needs. Physical health conditions may mimic, accompany, or be caused by mental health problems in people with ID. The diagnosis of a non-organic diagnosis can only be made after an appropriate physical examination and investigations. There are many positive aspects to doing a physical examination and confidence in performing them requires practice.

### **Clinical Tips**

Take a thorough history and particularly try to establish the concerns of the person with ID and their carers. If the person who is most concerned is not with the person, consider either phoning them directly or writing to them. Use any useful information such as summary sheets from their GP with their significant past medical history and current medication. Ask to see their latest care plan and any health action plans as well as any weight charts. Before you start a physical examination, attempt to find out how the person with ID is likely to respond to touch. You will need to establish if the person with ID has capacity to consent to an examination. Find a chaperone that is trusted and well known to the person with ID. Set up the room for success by using a quiet room the person with ID is comfortable with, such as their own bedroom. Ensure there is good lighting and the room is adequately heated, especially as the person may need to remove their clothing at least partially. After washing your hands and introducing yourself, explain what you are going to do and demonstrate either on yourself or the chaperone before you proceed. The physical examination starts from the moment you first see the person as you observe their general appearance, dress, gait, repetitive movements, mobility, and how they interact with others and themselves. Continue to observe and think throughout the examination, try to examine in a respectful manner and avoid causing pain. It is always good practice when concerned about a person with an ID to try and talk to them on their own to see if there are stresses

or concerns they do not want to discuss in front of carers.

In 2016 the report “Improving the physical health of adults with severe mental illness: essential actions” was published by the Academy of Medical Royal Colleges and the Royal Colleges of General Practitioners, Nursing, Pathologists, Psychiatrists, Physicians, the Royal Pharmaceutical Society and Public Health England [10]. Among the recommendations included a requirement for mental healthcare providers to ensure National Early Warning Score that basic medical equipment is provided. They also recommended the use of the National Early Warning Score (NEWS) system in mental healthcare settings by staff trained in its use to enable the early recognition of acute illness and appropriate action to be taken in a timely way. In assessing acute illness, the NEWS (see Box 20.2), is based on a simple scoring system in which a score is allocated to physiological measurements already undertaken when patients present to, or are being monitored in hospital. In order to complete these you will need a thermometer, watch or mobile phone with second timer, sphygmomanometer and pulse oximeter.

Box 20.2: Six simple physiological parameters form the basis of the scoring system

1. Respiratory Rate
2. Oxygen Saturation
3. Systolic Blood Pressure
4. Pulse rate
5. Level of Consciousness or new confusion
6. Temperature

Reproduced from: Royal College of Physicians. National Early Warning Score (NEWS) 2: Standardising the assessment of acute-illness severity in the NHS. Updated report of a working party. London: RCP, 2017

After trying to establish these vital signs aim to conduct a systematic head to toe system assessment (see Box 20.3).

Box 20.3: Components of a Systematic Physical Examination

- Body Mass Index based on up to date height and Weight
- Auditory and Visual assessment
- Oral health
- Dermatological assessment
- Neurological assessment
- Cardiorespiratory assessment

Assessing pain requires particular attention, as this can be difficult to ascertain and may be managed. The ‘Non-Communicating Adults Pain Checklist’, is an 18-item behavioral scale, which can be used to assess pain levels in adults with ID [12]. The model reflects two categories of pain responses: a basic response consisting of physiological measures and body reaction and an advanced response consisting of vocal and emotional reactions and facial and protective expressions and may be a reasonable tool to assess pain.

There are certain conditions, which are more likely to occur and require proactive and regular structured assessment. For example, gastrointestinal disorders such as reflux and constipation commonly present with change in behaviour that may remain unrecognised as an underlying cause or poorly managed leading to further complications. Bowel function can be affected by underlying conditions such as Down syndrome, metabolic disorder such as hypothyroidism, but can also be a complication of medications (anticonvulsants, antipsychotics, benzodiazepines, and tricyclic antidepressants) that can reduce intestinal motility (Table 20.1).

Table 20.1: Symptoms, Signs and Complications related to common causes of constipation in ID

Common Causes	Symptoms, Signs and Complications
<b>Medications</b> <ul style="list-style-type: none"> <li>➤ Anticonvulsants</li> <li>➤ Benzodiazepines</li> <li>➤ Antipsychotics</li> <li>➤ Calcium and iron supplements</li> <li>➤ Antacids</li> </ul>	Food Refusal Agitation/Aggression Bloating/tender abdomen Irregular/infrequent bowel habit Vomiting Haemorrhoids Rectal bleeding Obstruction
<b>Lifestyle Risk factors</b> <ul style="list-style-type: none"> <li>➤ Reduced fluid/fibre intake</li> <li>➤ Sedentary lifestyle</li> <li>➤ Restricted mobility</li> </ul>	
<b>Neuromuscular Disorders</b> <ul style="list-style-type: none"> <li>➤ Spina bidida</li> <li>➤ Megacolon</li> </ul>	
<b>Endocrine Disorders</b> <ul style="list-style-type: none"> <li>➤ Hypothyroidism</li> </ul>	

A structured approach to reviewing a person's health requires a systematic assessment that takes into account underlying risk factors, complications of therapy, and the need for a coordinated approach across health and care settings. For example, people with ID have significant oral health problems from an early age which requires intervention at an individual/carer level through education and therapy; review of medications (for example, anticonvulsants such as Phenytoin which cause gingival overgrowth and enlargement); access to regular dental assessment as well as treatment by a hygienist and appropriate surgical interventions. Targeted investigations when the clinical findings on examination cannot be explained should include the following:

Box 20.4: Targeted Investigations

Blood Investigations

- Full Blood Count and C reactive protein
- Electrolytes
- Liver Function
- Random glucose and glycosylated HbA1c
- Thyroid Function Test
- Drug levels

Mid-Stream Urine Sample analysis

Chest x-ray

### **Health promotion**

Annual health checks for adults with intellectual disabilities have been shown to be effective in identifying new health needs [13], providing an opportunity to review concurrent comorbidities (e.g. epilepsy and diabetes), and to offer health promotion with information (e.g. access to dietary and smoking cessation services) as well as access to national screening programmes. In the UK, this has been an enhanced service with additional payment to GP practices to undertake but a multidisciplinary team

approach involving the wider primary and community health care providers is needed to undertake health checks successfully.

### **Medication: The impact of medication on physical health**

Drug therapy is a useful in managing mental disorders however the adverse effects of medication can have direct impacts on a person with ID and affect their physical health and their Quality of Life (QoL). Prescribing clinicians may not consider the impact of drug therapy on the person's quality of life whilst seeking to treat the symptoms of mental illness. As the number of psychotropic medications that a person uses increases they negatively affect the person's QoL especially where two or more drugs are prescribed [14]. The impact on the person's QoL, as measured using the Intellectual Disability Quality of Life-16 Scale (IDQoL-16), does not appear to affect the care plan since the physicians do not alter the drug regimen [14].

Psychotropic medication affects physical health through metabolic and motor side effects associated with them. The metabolic side effects include weight gain, hormonal changes, abnormal blood lipid and blood sugar levels, and high blood pressure while motor effects manifest as movement disorders. Generally, first generation antipsychotics (FGA) exert motor and hormonal effects while second generation antipsychotics (SGA) predominantly exhibit metabolic effects but not exclusively so. People with ID are especially sensitive to the adverse effects of all medication types and not just to psychotropic medication.

### **Motor Side Effects of Antipsychotic medication**

The motor effects are referred to as extrapyramidal side effects (EPSE) that cause dystonic reactions affecting large and small muscles of the eyes, neck, trunk, and limbs to which people with ID are especially vulnerable. Tardive dyskinesia (TD) is a known effect of FGA that results often from prolonged use of antipsychotic medication [15]. The risk factors for developing TD include cognitive impairment, age, more severe ID, and chronic use of medication [16]. Clinicians need to be aware that the risks are higher in people with ID and be informed about the signs of TD and how to treat it. Using SGA drugs may reduce the risk of motor side effects but not necessarily eliminate them. TD has been reported in a person with ID using Aripiprazole where the mechanism of action is partial antagonism of Dopamine and Serotonin receptors [17]. Risperidone is known to cause urinary incontinence with greater risk in people with Autism and ID that can be eliminated by reducing the dose or withdrawing the drug [18]. In clinical care the DISCUS (Dyskinesia Identification System: Condensed User



Scale) is a useful rating scale to assess for the presence of motor side effects and TD that are found more significantly in people with ID using psychotropic medication compared with those not using medication [19].

### **Neuroleptic Malignant Syndrome**

A serious and potentially life-threatening effect of psychotropic medication is Neuroleptic Malignant Syndrome (NMS) [20]. ID is a recognized risk factor in developing NMS and is more likely to occur where polypharmacy, using five or more drugs, is practiced [21]. Clinicians working with people with ID need to be aware of and alert to the signs of NMS that include: raised temperature, fluctuating level of consciousness, aggression, variable blood pressure and heart rate, increased muscle rigidity along with raised creatine kinase (CK) enzyme levels. The clinical signs could be attributed to other disorders, for example, delirium, infection, and heart failure, or to ‘challenging behaviour’ by staff not familiar with the signs of NMS. Accurate and timely diagnosis of NMS is vital to ensure appropriate treatment in hospital is instigated to reduce the high risk of death. NMS is associated with FGA but there is a growing evidence of NMS following treatment with second-generation antipsychotics such as Quetiapine [22, 23].

### **Metabolic Effects of antipsychotic medication**

People with ID are more prone to being overweight and obese compared to the general population especially where the person has a mental disorder [24]. There are a variety of reasons for this that includes sedentary lifestyles with few opportunities to exercise, high calorific – low nutrition diets, and using weight-inducing medication. Weight gain can be a manifestation of metabolic syndrome that increases the risk of developing diabetes mellitus, cardiovascular disease, and cancers. It is notable however; that people with severe ID are more likely to be underweight and attention should be paid to their weight status [25].

The metabolic effects of second-generation antipsychotic medication especially Risperidone, include weight gain, increased cardiovascular disease risk factors, and osteoporosis related to raised Prolactin levels due to Dopamine D2 receptor blockade. Elevated Prolactin levels over long periods of time affect sexual function manifesting as gynaecomastia or galactorrhea in men and women and amenorrhoea in women. In addition, the potential development of prolactinoma, and insulin resistance predispose people to bone fracture especially in a population that is already vulnerable to bone injury [26].

Efforts to discontinue or reduce antipsychotic medication can lead to beneficial gains in reducing weight and blood pressure [15]. In practice, simple measures such as measuring weight and blood pressure and monitoring for side effects in line with practice guidance are feasible [27]. Sharing written information presented in easy-read format can help people with ID and their carers to understand the importance of managing weight and its benefits and lead to reductions in Body Mass Index [28].

### **Assessing for adverse effects of antipsychotic medication**

For people with ID, using psychotropic medication can have potentially serious and disabling physical effects that could impair a person's level of functioning and their ability to engage in community activities. For this reason, assessment for the presence of adverse effects is good practice. Clinicians and support staff can use objective rating scales to assess for the presence of motor or metabolic side effects. The GASS (Glasgow Antipsychotic Side Effect Scale) [29] is useful in assessing for metabolic effects while the MEDS (Matson Evaluation of Drug Side effects) and DISCUS for motor effects [30, 31]. Incorporating assessment for side effects in to clinical practice should help the detection of potentially disabling motor side effects of medication.

### **Physical Environment and ID**

Physical exercise is important in maintaining physical health in people with ID but they may not always have the opportunity to avail of exercise activities. People in hospital inpatient services are at risk of developing Metabolic Syndrome because of the confined environment and legislative restriction on a person's liberty as part of the care plan in managing mental disorder that can limit exercise opportunities. In addition, the sedative effects of medication lead to weight gain and the possibility of poor motivation among staff to help people to exercise [32]. It is essential therefore, that support staff are aware of the importance of physical exercise to a person's well-being and its beneficial effects on mental health and thus promote opportunities to exercise during in-patient admissions.

Physical activity can be incorporated in to care plans that could make a difference to the person's lifestyle by using the admission as an opportunity for health promotion by introducing new activities and habits to the person. As with all of us, physical activity should be regular, fun and socially inclusive, often working better if music is incorporated. A full review of a person's physical health while in an in-patient service is good practice to identify physical morbidity and provide an opportunity to treat physical health disorders such as long-term conditions.

Bone health in people with ID is poor especially as they age [33] and they are prone to fractures because of immobility, fewer opportunities to exercise and low vitamin D levels [34]. Prescribers may not be aware of the risk factors for osteoporosis in people with ID [35, 36] but should be informed about the impact of medication and anti-epileptic drugs (AED) in particular on bone health. Inpatient admissions are likely to compound the deficiency if the person has limited access to sunlight.

People with Autism are prone to sensory sensitivity affecting all the senses because of difficulties in processing sensory information [37]. An environment that has hard surfaces predisposing to loud noises, or the presence of others making noise and visually uncomfortable surroundings can all directly affect a person with Autism, leading to adverse changes in their behaviour. For these reasons, clinicians should be aware of the potential impact that physical environments can have on the behavioural presentation of a person with Autism.

### **Behavioural Phenotypes and physical health**

Behavioural phenotypes are descriptions of behaviour associated with specific genotypes ‘a characteristic pattern of social, linguistic, cognitive and motor observations consistently associated with a biological or genetic disorder’ [38]. They are more common among people with ID and include Prader-Willi syndrome, Down’s syndrome, and Williams syndrome. Behavioural phenotypes can have a constellation of multi-system physical disorders associated with them. For this reason, it is important for the clinician to consult current knowledge and evidence on physical disorders in people with behavioural phenotypes [39]. In Prader-Willi syndrome obesity is directly related to the genetic microdeletion and in Smith-Magenis syndrome the pain threshold is higher posing risks to their safety. People with Down’s syndrome are liable to gain weight and have musculoskeletal difficulties. People with behavioural phenotypes have a greater prevalence of mental disorders and therefore likely to require drug therapy to manage the disorder potentially could affect their physical health. For the clinician, it is important to be aware of the physical characteristics of behavioural phenotypes and the impact that treatment plans could have on the person’s physical health whether it is the use of drug therapy or opportunities to exercise.

### **Prescribing practice in ID**

The prevalence of psychotropic use is high in people with ID and often without clear indications for their use where medication is prescribed ‘off-licence’ to manage behaviour [40, 41]. Using antipsychotic medication in people with ID to manage

behaviour or mental disorders is a contentious issue as evidenced by the STOMP campaign in England to reduce the prevalence of antipsychotic prescribing among people with ID [42]. People with ID may require complex drug regimens to manage physical health problems along with behavioural or mental disorders and as they age multi-morbidity is more common among older people with ID [43]. Therefore people with ID are more exposed to potential side effects because of complex drug regimens. The efficacy of anti-epileptic drugs (AED) can be adversely affected by other medications interacting directly or interfering with their metabolism by the body. Prescribing errors are a risk to people with ID especially among older people using many drugs and those who are more physically and intellectually able [44]. To manage drug regimens, it is advisable to use what is necessary and to review regularly the regimens to reduce the risk of adverse effects from combinations of medication [45].

A useful approach to prescribing to people with ID is to “start low and go slow” [46]. Practical guidance is available to support prescribing practice and to gain the person’s consent to treatment where possible [47]. Where a person does not have mental capacity to consent to treatment, prescribers should adhere to legislation or good practice guidance in effect in their jurisdiction.

### **Liaison Nursing in Intellectual Disability Services**

The role of the Liaison Nurse in ID Services in the UK is important where they serve as a conduit between healthcare staff in hospital settings and specialist ID services enhancing access to healthcare for people with ID. Such practitioners make a distinct contribution in raising awareness of and educating non-specialist clinicians on the health needs of people with ID that help to reduce the health inequalities that confront people with ID. Liaison nurses have been identified as key enablers in implementing strategies and policies on the care of people with ID among staff in general hospitals [48]. The Liaison Nurse in ID is a valuable resource when working with people with ID in health care settings that is appreciated by staff in hospital services [49].

#### **Box 20.5: Good Practice Tips**

- Assess for physical disorders
- Consider alternatives to drug therapy
- Assess potential impact of adverse effects before prescribing

- ‘Start low and go slow’
- Monitor for adverse effects
- Monitor weight, BP, HR, waist circumference
- Liaise with Primary Care clinicians

### **Summary**

People with ID have a significantly higher risk of acute and long-term physical and mental health problems that may present in complex ways including behaviours that challenge which makes it difficult for carers and clinicians to recognise. Early recognition and treatment requires a structured approach such as regular health checks, good communication and clinical skills to provide individual and systematic approach to gathering as much history and examination information before investigating and considering treatment options. Internationally, primary care remains the main point of access health care with variable provision to specialist care [50]. Thus, consideration should be given to making reasonable adjustments to improve access to mainstream health care for people with intellectual disability. If the treatment is not working it remains vital to re-evaluate quickly and ask others for help in a timely manner in order to ensure distress is alleviated and the illness does not deteriorate. Carers do not usually delay seeking help for people with ID they are concerned about, but health care professionals will often delay investigating until the situation is life threatening [3]. If a person with ID presents back to their GP or clinician in primary care after an initial treatment appears not to be working it is important to refer quickly to secondary care for a more detailed assessment. Practices such as ‘three strikes and you are in’ may lead to considerable delays in diagnosis and worsening of the person’s condition. Polypharmacy and use of antipsychotics potentially contribute further to the illness burden of people with ID with FGA causing extrapyramidal side effects and newer antipsychotics increasing the risks of metabolic and cardiac side effects. Regular medication review by their GP and practice pharmacist is needed at least annually and preferably 6 monthly with reconciliation of medication after hospital discharge to ensure medication adjustments are safely continued in primary care. Including a clear reason for the medication in the prescription instructions (e.g. 2 tablets at night for constipation) reduces the risks of medication errors.

Finally, we must all play our part in breaking down the barriers across primary and secondary health care as well as social services. Poor communication, lack of mutual respect and professional differences between multiple agencies can lead to poor access to health care. Only then will we challenge the status quo that Baroness Hollins has highlighted and ensure both horizontal and vertical access in our health and social care systems and meet some of the unmet needs of this vulnerable group.

### **Case Study 1**

Katie is a 56 year old woman with mild ID living in the community, where she receives 24-hour support. She has diagnoses of Bipolar Affective Disorder with associated challenging behaviours, and memory difficulties.

Her physical health difficulties include Type 2 Diabetes Mellitus, a diencephalic tumour, and mobility difficulties due to bunions. The brain tumour was an incidental finding and is kept under review. She is post-menopausal.

Drug therapy includes Quetiapine for its antipsychotic properties, and Lithium Carbonate as a mood stabiliser. She also uses Metformin and Gliclazide to manage her Diabetes.

Her weight is 96kg with an associated Body Mass Index of 38.

### **Clinical issues**

- The impact of psychotropic medication on her physical health and Quality of Life
- The side effects of psychotropic medication
- The use of medication to manage physical health problems
- The psychiatric effects of a brain mass
- Monitoring of physical and mental health

### **Management**

Drug rationalisation and optimisation was undertaken because of the apparent impact of Quetiapine and Lithium Carbonate on her metabolism and weight. A fine tremor affecting her upper limbs was also evident. The fine tremor could be secondary to the use of Lithium Carbonate or represent a sign of changes in the brain tumour.

Quetiapine was substituted with Aripiprazole, leading to a reduction in weight to 72kg with improved glycaemic control and withdrawal of hypoglycaemic medication.

Lithium Carbonate was replaced with Semisodium Valproate with a reduction in signs of fine tremor. Semisodium Valproate led to hypernatraemia that was replaced with Lamotrigine for its mood stabilising properties.

Her mobility improved with the loss of weight. Review by a Podiatrist has been essential as part of monitoring Katie's hallux valgus deformity.

Thyroid levels were checked because of the thyroid effects of Lithium Carbonate, and were within the normal range.

The risk of memory problems and dementia are increased because of both Katie's Diabetes and the presence of her brain tumour.

Regular health checks by the primary care physician and review by the psychiatrist are essential in supporting her to manage her long-term conditions.

## **Case Study 2**

Gina is a 23 year old female with severe ID and limited verbal communication, whom is cared for by her family. She was first seen by her GP on a home visit, with a two-day history of reduced mobility and apparent right knee discomfort on movement, and was struggling to walk to the bathroom. None of her family carers reported any obvious witnessed fall or injury. On examination she was walking with a slight outwardly rotation to the right side, with full range of movement of her right knee, but appeared to have some distress on movement of the joint.

Her GP referred her for an x-ray of the knee, which showed no evidence of injury. The problem persisted and her mobility reduced further, with associated pain and distress. The GP referred into hospital services for further investigations which took a significant time to arrange (over a week). Eventually, due to escalation in concerns from the family as Gina became unable to weight bear, the GP arranged admission to the hospitals orthopaedic assessment unit.

After over 2 weeks in hospital she had multiple blood tests and a further x-ray revealed fracture in the distal head of her right femur. There was evidence on the x-ray of a bone cyst that was preventing the fracture from healing and a full leg cast applied to maintain the leg while the cyst is being investigated. A referral was made to a tertiary centre for an opinion on treatment.

On return from assessment in tertiary centre, Gina was transferred to local hospital for preparation for discharge.

## **Clinical Issues**

- Communication with patient with limited verbal and non-verbal skills
- Assessment of pain and physical examination
- Coordinating health and social care in a community setting

### **Management**

On discharge the family found they were struggling to cope with Gina's physical care. They had attempted to contact social services, as the family carers were unable to provide care due to lack of information from discharge.

The family were struggling to mobilise Gina from her bed to her wheelchair, as well as then to the toilet and the sofa, as she was non-weight bearing and had a full cast on her right leg. After discharge from hospital Integrated Community Therapy Team visited with the following recommendations:

- Community occupational therapists (OT) assessed for outside ramps
- Leg extender fitting to her wheel chair
- Banana board provided for use from bed to wheelchair
- Social assessment for increase in care package to help with washing and personal care in bed until suitable mechanisms for moving and handing are in place.
- Therapists to assess transfers, particularly if some heights are feasible (wheelchair to sofa for example).
- OT to assess bathing options
- OT to assess feasibility of specialist seating
- Independent social care provider to support Gina and her family to commence supporting with personal care
- Community Learning Disability team for ongoing support and care coordination
- GP to review analgesic control on a regular basis using Disability Distress Assessment Tool (DISDAT)

### **Multiple choice Questions**

#### **Questions**

1. Common causes of constipation in adults with intellectual disability include:  
Please select the single most appropriate answer.
  - a. Hypercalcaemia
  - b. Hyperthyroidism



- c. Magnesium Hydroxide
- d. Phenytoin
- e. All of the above

2. Tardive Dyskinesia

Please select the single most appropriate answer.

- a. Increased risk with age
- b. Is less likely with SGA (second generation antipsychotics) than FGA (first generation antipsychotics).
- c. Pyridoxine may be beneficial in reducing severity of symptoms
- d. Quetiapine and Clozapine can be used following appearance of TD
- e. All of the above

3. Which of the following are Metabolic side effects of SGAs?

Please select the single most appropriate answer.

- a. Menorrhagia
- b. Galactorrhoea
- c. Osteoporosis
- d. Insulin resistance
- e. Xanthomas

4. Behaviour associated with behavioural phenotypes include:

Please select the single most appropriate answer.

- a. Prader-Willi Syndrome and obesity
- b. Smith-Magenis Syndrome and higher pain threshold
- c. Down Syndrome and musculoskeletal disorders
- d. Williams Syndrome and difficulty in concentration
- e. Lesch-Nyhan syndrome and self-injurious behaviour
- f. All of the above

5. Cardiovascular disease is NOT a common complication in the following conditions:

Please select the single most appropriate answer.

- a. Down Syndrome
- b. Fragile-X syndrome

- c. Turner Syndrome
- d. Prader-Willi Syndrome
- e. Williams Syndrome

### Answers

- 1. A.
- 2. E.
- 3. B, C, D, E
- 4. F.
- 5. D.

### References

1. Emerson E., Baines S., Allerton L., Welch V. *Health Inequalities and people with learning disabilities in the UK*. 2011. IHAIDD Observatory, Public Health England, London.
2. Glover, G., Williams, R., Heslop, P., Oyinlola, J., and Grey, J. Mortality in people with intellectual disabilities in England. *Journal of Intellectual Disability Research*. 2016 doi: [10.1111/jir.12314](https://doi.org/10.1111/jir.12314).
3. Heslop, P, Blair, PS, Fleming, P, Hoghton, M, Marriott, A, and Russ, L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet*. 2013; (published online Dec 11.)[http://dx.doi.org/10.1016/S0140-6736\(13\)62026-7](http://dx.doi.org/10.1016/S0140-6736(13)62026-7)
4. Public Health England. *Joint Health and Social Care Self-Assessment Framework* 2014.2015 [www.improvinghealthandlives.org.uk/publications/1246/Joint Learning Disabilities Health and Social Care Self-Assessment Framework 2014](http://www.improvinghealthandlives.org.uk/publications/1246/Joint_Learning_Disabilities_Health_and_Social_Care_Self-Assessment_Framework_2014) [accessed 1/11/2016].
5. Cooper S-A, McLean G, Guthrie B, et al. Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Fam Pract*. 2015;16:110.

6. McCarron M, Swinburne J, Burke E, McGlinchey E, Carroll R, McCallion P. Patterns of multimorbidity in an older population of persons with an intellectual disability: results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA) Res Development Disabilit. 2013;34:521–7. doi: 10.1016/j.ridd.2012.07.029
7. Collacott, R.A., Cooper, S.A. Branford, D. and McGrother, C. Epidemiology of Self Injurious Behaviour in Adults with Learning Disabilities. British Journal of learning Disabilities 173;428 -432(1998).
8. McGrother, C.M., Bhaumik, S., Thorp, C.F., Hauck, A., Branford, D., Watson, J.M., Epilepsy in adults with intellectual disabilities: Prevalence, associations and service implications, Seizure, Volume 15, Issue 6, September 2006, Pages 376-386, ISSN 1059-1311, <http://dx.doi.org/10.1016/j.seizure.2006.04.002>.
9. Mason, J. and Scior, K. ‘Diagnostic Overshadowing’ Amongst Clinicians Working with People with Intellectual Disabilities in the UK. Journal of Applied Research in Intellectual Disabilities. 2004. 17: 85–90. doi: 10.1111/j.1360-2322.2004.00184.x
10. Working Group for Improving the Physical Health of People with SMI (2016) Improving the physical health of adults with severe mental illness: essential actions (OP100). Royal College of Psychiatrists. <http://www.rcpsych.ac.uk/files/pdfversion/OP100.pdf>
11. Royal College of Physicians. National Early Warning Score (2012). (NEWS) <https://www.rcplondon.ac.uk/projects/outputs/national-early-warning-score-news>
12. Meir L, Strand LI and Alice K. A model for pain behavior in individuals with intellectual and developmental disabilities. Res Dev Disabil. 2012. 33: 1984-1989
13. Buszewicz M., Welch C., Horsfall L., Nazareth I., Osborn D., Hassioti A., Strydom A. Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study, The Lancet Psychiatry. 2014. 1(7), 522-530
14. Scheifes A, Walraven S, Stolker JJ, Nijman HL, Egberts TC, Heerdink ER. Adverse events and the relation with quality of life in adults with intellectual disability and challenging behaviour using psychotropic drugs. Research in developmental disabilities. 2016 Mar 31; 49:13-21.

15. de Kuijper G, Mulder H, Evenhuis H, Visser F, Hoekstra PJ. Effects of controlled discontinuation of long-term used antipsychotics on weight and metabolic parameters in individuals with intellectual disability. *Journal of clinical psychopharmacology*. 2013 Aug 1; 33(4):520-4.
16. Matson JL, Fodstad JC, Neal D, Dempsey T, Rivet TT. Risk factors for tardive dyskinesia in adults with intellectual disability, comorbid psychopathology, and long-term psychotropic use. *Research in developmental disabilities*. 2010 Feb 28; 31(1):108-16.
17. Lim HK, Pae CU, Lee C, Lee CU. Tardive dystonic symptoms associated with aripiprazole treatment. *Progress in Neuro-Psychopharmacology and Biological Psychiatry*. 2008 Feb 15; 32(2):589-90.
18. Kumazaki H, Watanabe K, Imasaka Y, Iwata K, Tomoda A, Mimura M. Risperidone-associated urinary incontinence in patients with autistic disorder with mental retardation. *Journal of clinical psychopharmacology*. 2014 Oct 1; 34(5):624-6.
19. Matson JL, Mayville EA, Bielecki J, Smalls Y, Eckholdt CS. Tardive dyskinesia associated with metoclopramide in persons with developmental disabilities. *Research in developmental disabilities*. 2002 Jun 30; 23(3):224-33.
20. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub; 2013 May 22.
21. Shalev A, Hermesh H, Munitz H. Mortality from neuroleptic malignant syndrome. *Journal of Clinical Psychiatry*. 1989 Jan.
22. Dan A, Bharadwaj R, Grover S. Neuroleptic malignant syndrome with use of quetiapine in mental retardation. *Psychiatry and clinical neurosciences*. 2009 Apr 1; 63(2):255-6.
23. Gortney JS, Fagan A, Kissack JC. Neuroleptic malignant syndrome secondary to quetiapine. *Annals of Pharmacotherapy*. 2009 Apr 1; 43(4):785-91.
24. Gazizova D, Puri BK, Singh I, Dhaliwal R. The overweight: obesity and plasma lipids in adults with intellectual disability and mental illness. *Journal of Intellectual Disability Research*. 2012 Sep 1; 56 (9):895-901.
25. Moran R, Drane W, McDermott S, Dasari S, Scurry JB, Platt T. Obesity among people with and without mental retardation across adulthood. *Obesity Research*. 2005 Feb 1; 13(2):342-9.

26. Hellings JA, Zarcone JR, Valdovinos MG, Reese RM, Gaughan E, Schroeder SR. Risperidone-induced prolactin elevation in a prospective study of children, adolescents, and adults with mental.
27. Teeluckdharry S, Sharma S, O'Rourke E, Tharian P, Gondalekar A, Nainar F, Roy M. Monitoring metabolic side effects of atypical antipsychotics in people with an intellectual disability. *Journal of Intellectual Disabilities*. 2013 Sep 1;17(3):223-35.
28. Mann J, Zhou H, McDermott S, Poston MB. Healthy behavior change of adults with mental retardation: Attendance in a health promotion program. *American Journal on Mental Retardation*. 2006 Jan; 111(1):62-73.
29. Waddell L, Taylor M. A new self-rating scale for detecting atypical or second-generation antipsychotic side effects. *Journal of Psychopharmacology*. 2008 May 1; 22(3):238-43.
30. Matson, J. L., Mayville, E. A., Bielecki, J., Barnes, W. H., Bamburg, J. W., & Baglio, C. S. (1998). Reliability of the Matson Evaluation of Drug Side Effects scale (MEDS). *Research in Developmental Disabilities*, 19, 501–506.
31. Kalachnik, J. E., & Sprague, R. L. (1993). The Dyskinesia Identification System Condensed User Scale (DISCUS): Reliability, validity, and a total cut-off for mentally ill and mentally retarded populations. *Journal of Clinical Psychology*, 49, 177–189.
32. Room B, Timmermans O, Roodbol P. The prevalence and risk factors of the metabolic syndrome in inpatients with intellectual disability. *Journal of Intellectual Disability Research*. 2016 Jun 1; 60(6):594-605.
33. Bastiaanse LP, Mergler S, Evenhuis HM, Echteld MA. Bone quality in older adults with intellectual disabilities. *Research in developmental disabilities*. 2014 Sep 30; 35(9):1927-33.
34. Frighi V, Morovat A, Stephenson MT, White SJ, Hammond CV, Goodwin GM. Vitamin D deficiency in patients with intellectual disabilities: prevalence, risk factors and management strategies. *The British Journal of Psychiatry*. 2014 Dec 1; 205(6):458-64.
35. Burke EA, McCallion P, Carroll R, Walsh JB, McCarron M. An exploration of the bone health of older adults with an intellectual disability in Ireland. *Journal of Intellectual Disability Research*. 2016 Jan 1. doi: 10.1111/jir.12273.

36. Srikanth R, Cassidy G, Joiner C, Teeluckdharry S. Osteoporosis in people with intellectual disabilities: a review and a brief study of risk factors for osteoporosis in a community sample of people with intellectual disabilities. *Journal of Intellectual Disability Research*. 2011 Jan 1; 55(1):53-62.
37. Baranek GT, David FJ, Poe MD, Stone WL, Watson LR. Sensory Experiences Questionnaire: Discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry*. 2006 Jun 1; 47(6):591-601.
38. O'Brien G. Behavioural phenotypes: causes and clinical implications. *Advances in Psychiatric Treatment*. 2006 Sep 1; 12 (5):338-48.
39. Society for the Study of Behavioural Phenotypes <http://www.ssbp.org.uk/>
40. Sheehan, R., Hassiotis, A., Walters, K., Osborn, D., Strydom, A., & Horsfall, L. (2015). Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ*; 351:h4326
41. De Kuijper G, Hoekstra P, Visser F, Scholte FA, Penning C, Evenhuis H. Use of antipsychotic drugs in individuals with intellectual disability (ID) in the Netherlands: prevalence and reasons for prescription. *Journal of Intellectual Disability Research*. 2010 Jul 1; 54(7):659-67.
42. NHS England (2016). Stopping Overmedication in People with Learning Disability (STOMP LD) <https://www.england.nhs.uk/2016/06/over-medication-pledge/>
43. Hermans H, Evenhuis HM. Multimorbidity in older adults with intellectual disabilities. *Research in developmental disabilities*. 2014 Apr 30; 35(4):776-83.
44. Zaal RJ, van der Kaaij AD, Evenhuis HM, van den Bemt PM. Prescription errors in older individuals with an intellectual disability: Prevalence and risk factors in the Healthy Ageing and Intellectual Disability Study. *Research in developmental disabilities*. 2013 May 31; 34 (5):1656-62.
45. Mahan S, Holloway J, Bamburg JW, Hess JA, Fodstad JC, Matson JL. An examination of psychotropic medication side effects: Does taking a greater number of psychotropic medications from different classes affect presentation of side effects in adults with ID? *Research in developmental disabilities*. 2010 Dec 31; 31(6):1561-9.

46. Haßler F, Reis O (2010) Pharmacotherapy of disruptive behavior in mentally retarded subjects: a review of the current literature. *Dev Disabil Res Rev* 16:265–272.
47. Trollor JN, Salomon C, Franklin C. Prescribing psychotropic drugs to adults with an intellectual disability. *Australian Prescriber*. 2016 Aug; 39(4):126.
48. Tuffrey-Wijne I, Giatras N, Goulding L, E Abraham, L Fenwick, C Edwards, and S Hollins. Identifying the factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals: a mixed-methods study. Southampton (UK): NIHR Journals Library; 2013 Dec. (Health Services and Delivery Research, No. 1.13.) Available from: <https://www.ncbi.nlm.nih.gov/books/NBK259489/> doi:10.3310/hsdr01130
49. Brown M, MacArthur J, McKechnie A, Mack S, Hayes M, Fletcher J. Learning Disability Liaison Nursing Services in south-east Scotland: a mixed-methods impact and outcome study. *Journal of Intellectual Disability Research*. 2012 Dec 1; 56 (12):1161-74.
50. Bhaumik S, Kiani, R, Michael DM, et al. World Psychiatric Association (WPA) report on mental health issues in people with intellectual disability. *International Journal of Culture and Mental Health*. 2016. 9:4, 417-444, DOI: 10.1080/17542863.2016.1228687