



Credit: Pablo Pineda, Spanish actor with Down syndrome; Drivaspacheco  
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## Educational aims

- To understand general principles of health of people with intellectual disability and how this affects the healthcare professional's approach to asthma management.
- To understand how intellectual disability affects cognition, autonomy and communication, and therefore the ability of a person to self-manage asthma.
- To recognise ways of mitigating respiratory disease risk in people with intellectual disability.
- To describe ways for healthcare professionals to support people with intellectual disability and their caregivers in asthma management.



# Asthma in intellectual disability: are we managing our patients appropriately?

People with intellectual disability are a vulnerable group of people with asthma that has, to date, largely been ignored in the medical literature. Although guidelines for medication management for people with intellectual disability suggest asthma is treated as for other populations, there are special considerations that should be taken into account when managing asthma in this group. Due to their cognitive impairment as well as comorbidities, they are likely to require support with asthma self-management, including inhaler use. Their varying degrees of autonomy mean that there is often a need to provide education and information to both the person and their caregivers.

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**People with intellectual disability can require special support for asthma self-management, including inhaler use** <http://ow.ly/mAuR305vrGq>

Asthma affects 1-18% of the population in different countries [1]. In addition to affecting the quality of life of an individual and their family, it places a significant economic burden on society as a whole, through utilisation of healthcare services and increased healthcare costs [2]. As asthma is a chronic inflammatory disease, anti-inflammatory treatment is a mainstay of asthma management [3]. Commonly used inhalational devices to deliver asthma medications are the pressurised metered-dose inhaler, dry-powder inhaler and nebuliser.

People with intellectual disability constitute ~1% of the world's population [4]. It may be caused by any condition that impairs development of the brain before birth, during birth or in childhood [5]. Intellectual disability requires that a person have an intelligence quotient (IQ) <70, together with deficits in two or more adaptive behaviours such as self-care and communication. Intellectual

disability is also known as learning disability in some countries (e.g. the UK) and was historically referred to as mental retardation. The adaptive deficits result in the person's failure to meet developmental and sociocultural standards for independence and social responsibility [5]. Within intellectual disability, there is heterogeneity: persons may present with different functional abilities in regard to socialisation, communication, behaviour, cognition and self-care. Thus, autonomy, including ability to self-manage medication use, varies depending on the severity of the intellectual disability.

Intellectual disability has been classified as mild, moderate, severe and profound mental retardation [6]. People with mild intellectual disability (IQ 50-69) may acquire academic skills up to fifth- or sixth-grade level (corresponding to children without intellectual disability aged 10-12 years), and as adults, may develop sufficient social and vocational abilities

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to work and live independently, or in supervised apartments and group homes, with a minimum of external support [7]. Although varying in the ability to understand spoken, pictorial or sign language (receptive ability), and to express themselves, those with mild intellectual disability use speech as their predominant form of communication, with superficially adequate language skills [8].

Concerning health, people with intellectual disability experience the same range of conditions commonly found in the general population; however, numerous health problems occur with greater prevalence: epilepsy, gastrointestinal disorders, dental problems, orthopaedic conditions, mental illness, sensory disorders and respiratory infections [9]. Co-existing mental illness is particularly prevalent [10] and includes challenging behaviours; these are culturally abnormal behaviours such as self-injury and property destruction, which threaten the physical safety of the person or others [11]. There is often an underlying cause (*e.g.* physical pain), which the person is unable to communicate in the usual fashion. Challenging behaviours are often (poorly) managed with psychotropic medications [12].

People with intellectual disability have an increased risk of respiratory tract infections and chronic respiratory diseases, and respiratory diseases are a leading cause of mortality [13]. The pathophysiology varies depending on the nature of the developmental disability that led to the intellectual disability; for example, people with cerebral palsy may develop bronchiectasis [14].

This group experiences health inequality due to deficiencies in access to and the quality of healthcare provision, personal health risks and behaviours, communication difficulties, and decreased health literacy [15]. People with intellectual disability may struggle during consultations with healthcare professionals, both with communicating their health needs, and with understanding what is happening to them during medical examinations, tests and procedures. This is particularly pertinent for persons who are unable to speak or for those who use alternative or augmentative communication systems [16].

## Asthma and intellectual disability

There is a paucity of published research into asthma and its treatment in people with intellectual disability, particularly in adults. There are no data on the efficacy of asthma medications in people with intellectual disability to date, probably due to their exclusion from clinical trials.

### Prevalence and risk association

Studies conducted in both adults and children with intellectual disability have shown mixed results

with regard to the association between intellectual disability and asthma [17–21]. Most data regarding asthma in children with intellectual disability derive from studies of children with Down syndrome. Data from a health survey comparing them with control subjects showed higher caregiver-reported rate of previous asthma and “asthma attack” in the preceding 12 months, but this did not reach statistical significance [18]. Other studies have reported decreased asthma prevalence in children with Down syndrome [22–24]. It has furthermore been suggested that recurrent wheeze in children with Down syndrome has a multifactorial pathophysiology that is unique to Down syndrome and is not associated with allergic airway inflammation [25].

In adults, data derived from 28 primary care practices in the UK (1097 adults with intellectual disability) estimated the prevalence of asthma in adults with intellectual disability of 12% [19]. The authors noted that this was around twice the prevalence in the general population. Additionally, data from 314 primary care practices in Scotland, UK, suggested a prevalence of active asthma in the 8014 people with intellectual disability of 7.2%, as compared with 5.9% in the general population (OR 1.26, 95% CI 1.16–1.38) [20]. By contrast, MORIN *et al.* [21], in comparing the prevalence of chronic health conditions among people with intellectual disability and without, found no significant differences for asthma between the intellectual disability (7%) and general populations (8.6%). Moreover, when data were further stratified by the presence of Down syndrome, it was found that people with Down syndrome had a significantly lower co-occurrence of asthma (4.6% *versus* 7.6%,  $p < 0.05$ ). This seems to corroborate the finding in children. Further research in a larger cohort is warranted to confirm these findings.

Interestingly, the existence of intellectual disability has been found to complicate asthma outcomes. Case-control studies in adults with intellectual disability have shown that, compared with control patients admitted to hospital with asthma, those with severe disease who died were significantly more likely to have intellectual disability amongst other factors [26]. This led to British guidelines listing learning difficulties (which are present in people with intellectual disability) as a psychosocial risk factor for fatal asthma [27].

### Research in asthma management for people with intellectual disability

This is a very neglected area, possibly due to difficulties in recruiting people with intellectual disability for research studies; however, it can be done [28].

#### Diagnosis

The feasibility, repeatability and reproducibility of measuring airway resistance using the interrupter

technique (MicroRint; BD, Franklin Lakes, NJ, USA) in lieu of spirometry has been studied in 67 people aged 50 years or over with a mild, moderate or severe intellectual disability [29]. Airway resistance during tidal breathing has a good correlation with forced expiratory volume in 1 s, which is measured with spirometry [30] and has been used successfully in children with cerebral palsy [31].

### *Self-management*

Most research regarding self-management of chronic conditions in people with intellectual disability contains proxy responses rather than those of the people with intellectual disability themselves [32]. However, knowledge of asthma medication self-management by individuals with mild intellectual disability has been qualitatively explored to identify support needs and challenges for health professionals when educating them regarding inhaler use [33]. In this small sample of 17 people with intellectual disability, participants appeared to have a good understanding of the importance of using their inhaled asthma medications, as well as asthma triggers, and the difference between use of preventer and reliever medications. Both enablers and barriers to asthma medication self-management were identified in the domains of managing attacks, adherence, knowledge of side-effects and sources of information on correct use of inhalers. Based on the barriers identified in the study, it was recommended that healthcare professionals promote use of spacers and written asthma action plans as well as counsel people with intellectual disability about how to recognise and minimise side-effects of asthma medications. The study also revealed that autonomy for medication use varied, with individual motivation to self-manage asthma influenced by the level of support that was available.

Inhaler technique mastery has also been studied in people with mild intellectual disability, triangulating a qualitative examination of the training process in inhaler technique (facilitated with video recording) with established quantitative techniques (standard inhaler checklists) to give the first insights into how individuals with intellectual disability actually use their inhalers [34]. The study showed that prior to training, no participants correctly used any device. The most poorly used devices were pressurised metered-dose inhalers, with or without accessory devices (spacers). Inhalation steps were poorly performed across all devices. A number of barriers to correct inhaler use were identified including poor comprehension of breathing processes and poor dexterity.

Standard inhaler technique education was not suitable for the majority of persons in the study. The educator used analogies to explain the difference between the breathing processes inspiration (like sucking through a straw) and expiration (blowing

out candles). Patient training devices utilising whistles were also useful in teaching participants to use sufficient inspiratory force with a Turbuhaler (AstraZeneca, London, UK). Other researchers have found that sensory signals were useful in training children to use inhalers [35]. Although numbers were small, some individuals could be trained to inhaler technique mastery, with Accuhaler (Diskus; GlaxoSmithKline, Brentford, UK) being the most correctly used inhaler type. Behavioural techniques and repeated reinforcement are likely to be necessary.

### *Role of caregivers*

People with intellectual disability often need assistance with taking medications due to their cognitive, physical and often sensory impairments. In residential accommodation, support workers are involved in the asthma management of their clients, either administering or supporting their clients to administer asthma medications. However, there appears to be a lack of decision support available to assist in this process [36].

## **Asthma management and intellectual disability**

The Global Initiative for Asthma (GINA) [1] outlines strategies for diagnosis, assessment and management of asthma. In summary, the clinician should:

- make the diagnosis based on the history of characteristic symptom pattern and evidence of variable airflow limitation (the latter should be documented from bronchodilator reversibility testing or other testing).
- assess symptom control and future risk of adverse outcomes, as well as treatment issues such as inhaler technique and adherence, side-effects and comorbidities.
- assist the patient to achieve good symptom control, maintain normal activity levels and minimise future risk of exacerbations.
- provide the patient with education and skills for guided self-management, which may involve varying degrees of independence. Self-management is best achieved through a partnership between patient and healthcare professional; therefore, good communication skills are needed by healthcare professionals.
- provide inhaler skills training; encourage adherence with controller medication; provide asthma information; provide training in asthma self-management (self-monitoring of symptoms and/or peak expiratory flow, written asthma action plan and regular review) to control symptoms, and minimise risk of exacerbations and healthcare utilisation.

Other authors, in respect of asthma self-management specifically, have proposed that desirable patient behaviours involve behavioural and cognitive skills [37–40]. Individual patients are able to demonstrate varying levels of responsibility for self-management, depending on attributes such as education level and psychosocial factors [41]. In the general population, educating asthma patients in self-management improves health outcomes [42].

Management strategies such as those of GINA are likely to be difficult for healthcare professionals to implement for people with intellectual disability for a number of reasons. Firstly, in regard to diagnosis, cognitive deficits in people with intellectual disability may render spirometry problematic due to a lack of co-operation, and diagnoses are therefore usually based on observable symptoms [29]. As a result, “mild and moderate pulmonary problems may be missed and under treatment is to be expected, whereas over treatment is also possible because of the lack of objective monitoring of effects” [29].

Concerning assessment and symptom control, chronic health conditions and comorbidities are common in people with intellectual disability. These affect quality of life and it can be postulated that similarly to the situation in the elderly, these are likely to complicate the clinical features of asthma [43] as well as negatively influencing medication adherence [44, 45]. The high level of medication use (polypharmacy) in people with intellectual disability [46] may render the administration of inhaled medication more complex within overall medication taking. Physiological factors may complicate respiratory status and affect use of inhalers. Syndromes associated with intellectual disability may involve neuromuscular weakness, with loss of control of the larynx and pharynx, and ineffective cough, leading to aspiration [47]. Physical deficits which occur in people with intellectual disability, such as hypotonia and dyspraxia, are known to lead to inability of a person to actuate an inhaler, or a delay in actuation and inhalation [48].

The provision of self-management education and skills training in inhaler use for people with intellectual disability is complicated by the fact that people with intellectual disability often have problems with working memory, interpreting incoming information and actioning self-monitoring [49], which translates into difficulty in recognising symptoms of worsening health. Extrapolating from the elderly, cognitive impairment of people with intellectual disability may lead to a poor perception of airflow limitation and acceptance of dyspnoea as normal [1]. This may result in difficulty in actioning an asthma plan.

Furthermore, people with intellectual disability have varying communication abilities (expressive and receptive) and health literacy. Healthcare professionals need to be mindful of the impact of intellectual disability on how health messages are communicated, as people with intellectual disability often take things literally. Well-designed instructions decrease cognitive load

and health-related decision-making is likely to be enhanced for people with intellectual disability if specially adapted information materials are used [50].

Finally, when it comes to self-management, the “partnership” between patient and healthcare professional often has an additional factor to be considered in people with intellectual disability: the caregiver. Depending on individual circumstances, this may be a facilitator or a barrier. For example, family members or support workers may help with recognition of health issues and the provision of a medical history, but these caregivers may not be aware of some symptoms, and accurate symptom monitoring may be difficult.

## What needs to be done to improve the management of asthma for people with intellectual disability?

Management of asthma for people with intellectual disability needs to be addressed at policy, guideline and practice levels. At a policy level, identification of people with intellectual disability as a group needing special consideration with regard to asthma management is an important first step. Although people with “physical or mental disabilities” are recognised as a population group that may have specific needs across the spectrum of asthma care [51], elucidation of strategies to achieve nominated outcomes such as “increased capacity of people with asthma and their carers to take charge of their own asthma management” is lacking. There is a need to develop protocols for employed caregivers to support them to recognise different respiratory conditions in clients with intellectual disability, and take appropriate and timely action.

Future research that could inform policy might include:

- assessment of inhaler technique mastery of employed caregivers of people with intellectual disability
- development and testing of inhaler technique support resources in a format such as Easy English, to complement existing resources such as the Asthma UK publications “All About Asthma”, “Asthma Attack Card” and “Inhaler Card”
- further development of tailored inhaler technique training for people with intellectual disability, incorporating recognised behavioural strategies
- direct assessment of asthma control of people with intellectual disability (rather than the surrogate measure of prescribed inhaled corticosteroid dose). This will necessitate the development of an asthma control questionnaire

in Easy English that is applicable for people with intellectual disability.

When it comes to guidelines, there are no extant clinical practice asthma guidelines that include specific recommendations for people with intellectual disability. In particular, it would be useful to articulate how multidisciplinary healthcare professionals can work together to manage asthma in people with intellectual disability in the community who require additional guidance and support. One possibility may be by developing health support networks for healthcare professionals managing people with intellectual disability and asthma in supported accommodation. Establishment of health networks that enable collaborative practice between healthcare professionals has led to improved asthma outcomes when treating the general community [52].

As noted above, some people with intellectual disability have a significant burden of respiratory disease, of which asthma may be a subset. People with severe to profound intellectual disability are at risk of pneumonia and aspiration pneumonia. Risk factors for aspiration include swallowing and eating difficulties, limited mobility, seizures and psychoactive medications [53]. Therefore, respiratory care recommendations that consider asthma management within the context of respiratory disease overall may be a useful addition for healthcare professionals managing people with intellectual disability. The following are suggestions based on Australian experience and consensus [53, 54]. The healthcare professional should:

- undertake a comprehensive review of the patient's respiratory status. As functional needs may change over time, regular review is essential.
- undertake preventative action to identify and manage respiratory risk factors for those with more severe levels of intellectual disability, who reside in accommodation supported by disability services.
- refer those with chronic severe respiratory disease to a specialist respiratory physician
- implement nonpharmacological strategies to reduce morbidity from respiratory disease such as: ensure influenza vaccine is up to date; promote smoking cessation; weight management; consider allergy testing for patients with asthma and sinusitis or allergic rhinitis.

In everyday practice, management strategies utilised by healthcare professionals will depend on the autonomy of the people with intellectual disability and their individual health profile. Healthcare professionals should take into account the person's living situation, comorbidities and polypharmacy (e.g. consider potential effects of psychotropic medications on respiratory status). However, as many of the considerations for asthma management for

people with intellectual disability mirror those for the elderly, in the absence of more specific information, management may be guided by general principles of asthma management in the elderly [1].

## Diagnosis

Confirm diagnosis with spirometry if possible. Alternatively, other types of pulmonary function tests may be easier in respect of patient cooperation (e.g. forced oscillation technique or interrupter technique).

## Device selection

- Consider muscle weakness, impaired vision and inspiratory flow when choosing devices.
- Involve the patient in the choice of inhaler; patients tend to have better technique with devices they find easiest to use [55]. Newer, more intuitive devices with fewer steps may be a good starting point.
- Prescribe nebulisers for people with intellectual disability with social/visual attentiveness deficits or for whom inhalers have proved unsuccessful.

## Education and training

- Teach inhaler technique to the person with intellectual disability and support persons/caregivers.

## Educational questions

- 1) Which of the following is not associated with intellectual disability?
  - a. Good expressive communication
  - b. Poor self-care
  - c. Sensory impairment
  - d. Mental illness
- 2) Diagnosis of asthma in people with intellectual disability may be difficult because
  - a. the person may have difficulty communicating their symptoms to the healthcare professional
  - b. the person may have difficulty monitoring their symptoms
  - c. the person may not be able to co-operate adequately with spirometry instructions
  - d. all of the above
- 3) The presence of intellectual disability has been shown to adversely affect asthma outcomes.
  - a. True
  - b. False
- 4) Nonpharmacological strategies to reduce morbidity from respiratory disease in people with intellectual disability include:
  - a. ensuring influenza vaccine is up to date
  - b. promoting smoking cessation
  - c. promoting exercise
  - d. allergy testing for patients with asthma and comorbidities such as sinusitis or allergic rhinitis

- Include competency assessment in caregiver training.
- Tailor information for people with intellectual disability wherever possible. However, inhaler technique instructions in Easy English are currently lacking.
- Supply information and decision support to caregivers (taking into account their health literacy) as well as the people with intellectual disability.
- Address patient and caregiver knowledge deficits with respect to medication side-effects.
- Support the person with intellectual disability with adherence to preventers and with symptom monitoring, including tailored written asthma action plans.

### Healthcare professional skills

- Healthcare professionals need excellent communication skills to successfully engage

with people with intellectual disability. As a guide, general strategies for communication with people with low health literacy may be useful, such as those in box 3.1 of the GINA strategy [1].

- Healthcare professionals also need to be proficient in inhaler technique, as for teaching any individual who uses inhalers.

### Conclusion

In summary, people with intellectual disability are at an increased risk of respiratory disease generally but the diagnosis of asthma may be difficult to ascertain. If a person with intellectual disability is prescribed inhaled medication, tailored individualised and regularly reinforced inhaler technique instruction is advisable. Education should additionally be directed to the person's caregiver.

### Conflict of interest

None declared.

### Suggested answers

- 1) a.
- 2) d.
- 3) a.
- 4) c.

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