What’s new in Developmental Disability (2021)

Some of the new information and major changes included in the Developmental Disability guidelines in eTG complete.

For the first time, the extensively revised Management Guidelines: Developmental Disability have been fully integrated into eTG complete as digital content, with relevant links to therapeutic advice in other parts of eTG complete. These guidelines aim to support general practitioners and other primary care providers caring for people of all ages with developmental disability.

Advice on managing children, adolescents, adults and people who are ageing now includes preventive health advice, common health problems and supports and services that are most relevant during each life stage.

Considerations related to consent, capacity and decision making for people with developmental disability are discussed, including supported decision making. A new topic on abuse, trauma and support for people with developmental disability has been developed to help clinicians understand and recognise the effects of abuse and trauma in this population and to mitigate these where possible with trauma-informed care and appropriate support. Reporting avenues for suspected abuse and trauma are summarised in a flowchart.

New content on the role of the general practitioner outlines aspects of care that general practitioners are often well placed to coordinate—it includes advice on referrals and tips to facilitate multidisciplinary management, which is recognised as integral to optimal care of people with developmental disability. The importance of a proactive approach is highlighted including annual comprehensive health assessments and identifying the person’s developmental disability syndrome or disorder (if it is not known) to guide anticipatory management. Information on assessment of developmental delay and disability and genetic testing is included where relevant.

This update also highlights ways in which general practitioners can improve access to health care for people with developmental disability, including establishing effective communication and other reasonable adjustments to overcome barriers to health promotion and chronic disease management. Tips for a general practice consultation include adaptations to history taking, ways to facilitate physical examinations and investigations, and how to engage caregivers. New advice is included on the National Disability Insurance Scheme (NDIS).
People with developmental disability are a diverse group who can have complex health conditions that manifest differently from those in the general population. In many cases, these are preventable. The guidelines focus on improving healthcare outcomes, with advice on recognition and targeted management of specific health problems commonly seen in people with developmental disability. The update includes guidance on oral and dental health, dysphagia, nutrition, epilepsy and seizures, sexuality and gender identity, menstrual management and contraception.

People with developmental disability are at increased risk of psychiatric disorders; assessment considerations have been updated to include tables of observable features to aid diagnosis in people who have difficulty communicating symptoms. Management advice for psychiatric disorders has also been revised.

Advice on challenging behaviour includes detail on behaviour support, and highlights the importance of a thorough investigation for contributing factors using a sociopsychobiomedical (biopsychosocial) approach. Legislation around restrictive practices is explained, to ensure healthcare practitioners are well informed and to avert the misuse of these practices by caregivers.

Specific syndromes and disorders most likely to be encountered in general practice are included, such as cerebral palsy, Down syndrome, fragile X syndrome, neurofibromatosis type 1 and 22q11.2 deletion syndrome (also known as velocardiofacial syndrome or DiGeorge syndrome). There is also a table of rarer syndromes and disorders associated with developmental disability, with links to specific medical management and further information.

The section on fetal alcohol spectrum disorder has been expanded to include information on assessing prenatal alcohol exposure and minimising risk. New advice emphasises opportunities to minimise long-term social and functional problems that can lead to adverse life outcomes.

The autism spectrum disorder topic focuses on diagnosis and functional assessment to identify the person’s developmental needs and inform early interventions; it has been updated to reflect current terminology.

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