3.11 Care of People with Intellectual Disability

The RCGP Curriculum: Clinical Modules

Version approved 19 January 2016
for implementation from 1 February 2016

➢ 3.11 Care of People with Intellectual Disability

Summary

As a general practitioner (GP) caring for adult patients with intellectual disability, you should:

- Recognise the importance of the principle of fairness and equality, irrespective of the innate abilities of each patient
- Recognise that in every consultation you must make the effort to identify, monitor and review the progress of all patients who have difficulties with communication, social relationships and managing their own affairs
- Recognise that respect for diversity may involve challenging the values of the local community and society in general
- Be aware of the atypical morbidity and mortality prevalent in patients with intellectual disability and the atypical presentation of acute and chronic physical and psychiatric disorders
- Be aware of the additional skills of diagnosis and examination needed in patients unable to describe or verbalise symptoms and where to obtain specialist advice and help
- Be aware of the effects intellectual disability has on the life history of the patient and family, particularly at times of transition
- Be aware of the effects intellectual disability has on the aging process, particularly in the development and recognition of dementia
- Understand the value of conducting regular (annual) health checks
- Appreciate the role of your own patients in the evolution of services for patients with intellectual disability. All mainstream services should offer patients with intellectual disability professional resources and facilities that are appropriate and tailored to their needs.
Knowledge and skills guide

Core Competence: Fitness to practise

This concerns the development of professional values, behaviours and personal resilience and preparation for career-long development and revalidation. It includes having insight into when your own performance, conduct or health might put patients at risk, as well as taking action to protect patients.

This means that as a GP you should:

- Be aware of your own feelings and attitudes to disability
- Be aware of your own feelings and attitudes to difficult decisions in the care of adults with intellectual disability

Core Competence: Maintaining an ethical approach

This addresses the importance of practising ethically, with integrity and a respect for diversity.

This means that as a GP you should:

- Respect the equal rights of all citizens to health care, health information and health promotion
- Appreciate that inclusion begins with and depends on commitment to the development of a fully accessible service
- Show respect for the patient’s right to make decisions about some aspects of their lives in accordance with the Mental Capacity Act 2005 in England and Wales, common law in Northern Ireland and the Adults with Incapacity (Scotland) Act 2000

Core Competence: Communication and consultation

This is about communication with patients, the use of recognised consultation techniques, establishing patient partnership, managing challenging consultations, third-party consulting and the use of interpreters.

This means that as a GP you should:

- Be aware of residential situations and daytime activities available locally to adults with intellectual disability, including those provided by the voluntary sector
- Be aware of how communicating via carers may affect the doctor–patient relationship
- Optimise communication through the use of consulting skills and communication aids
- Be aware of the issues of capacity and consent, and the mechanisms by which these can be determined
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**Core Competence: Data gathering and interpretation**

This is about interpreting the patient’s narrative, clinical record and biographical data. It also concerns the use of investigations and examination findings, plus the adoption of a proficient approach to clinical examination and procedural skills.

This means that as a GP you should:

- Describe how psychiatric and physical illness may present atypically in patients with intellectual disability because of sensory, communication and cognitive difficulties
- Demonstrate the necessary skills to conduct a physical and mental state assessment in a patient with intellectual disability with regard to the higher prevalence of some problems, such as respiratory conditions and epilepsy
- Understand the need to use additional enquiry, appropriate tests and careful examination in patients unable to describe or verbalise symptoms
- Understand the significance and prevalence of oropharyngeal disorders and dysphagia in people with intellectual disability and its relevance to the high prevalence of respiratory disorders in these patients

**Core Competence: Making decisions**

This is about having a conscious, structured approach to decision-making; within the consultation and in wider areas of practice.

This means that as a GP you should:

- Be aware of the concept of diagnostic overshadowing when a person’s presenting symptoms are put down to the disability, rather than the doctor seeking another, potentially treatable cause
- Understand the psychiatric disorders prevalent in the adult with intellectual disability and how their diagnosis, detection and management differ particularly with regard to –
  - emotional and behavioural disorders
  - bereavement reactions
  - anxiety and depression
  - schizophrenia
  - bipolar affective disorder
  - Alzheimer’s disease
  - Autism and autistic spectrum conditions
- Understand developmental disability and the neurologically based disorders that originate before birth and affect the patient throughout life. In particular, you need to understand the diagnosis and management of patients with autistic spectrum conditions
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Core Competence: Clinical management

This concerns the recognition and management of common medical conditions encountered in generalist medical care. It includes safe prescribing and medicines management approaches.

This means that as a GP you should:

- Understand the need to support adolescents with intellectual disability as they become adults and no longer have the multidisciplinary support of community paediatricians
- Create and maintain a register of adults with intellectual disability in the practice and correlate this to the shared local health and social services registers
- Understand the importance of the annual health check to an adult with intellectual disability
- Manage and undertake annual health checks within the primary care team and arrange the necessary referrals and follow-up of conditions detected by tailoring chronic disease management to the particular needs of this group of the practice population
- Understand your role in ensuring equal access to mainstream services, ensuring those services make ‘reasonable adjustment’ to the needs of patients with intellectual disability, whenever required
- Provide more time in the consultation in order to deal more effectively with people with intellectual disability

Core Competence: Managing medical complexity

This is about aspects of care beyond managing straightforward problems. It includes multi-professional management of co-morbidity and poly-pharmacy, as well as uncertainty and risk. It also covers appropriate referral, planning and organising complex care, promoting recovery and rehabilitation.

This means that as a GP you should:

- Be aware of likely associated conditions, the high mortality, the high morbidity and the difference in morbidity in people with intellectual disability compared to the rest of the population
- Understand how patients with borderline intelligence have difficulty coping with complex executive mental functions and how this can affect their behaviour
- Understand how health promotion can be overlooked in the care of patients with intellectual disability and the importance of tailoring health promotion to the needs of this special group particularly with regard to the difficulties of routine screening, such as cervical cytology, mammography, abdominal aortic aneurysm and bowel cancer screening
- Understand how adults with intellectual disability are subject to poly-pharmacy and how this can be made safer
Core Competence: Working with colleagues and in teams

This is about working effectively with other professionals to ensure good patient care. It includes sharing information with colleagues, effective service navigation, use of team skill mix, applying leadership, management and team-working skills in real-life practice, and demonstrating flexibility with regard to career development.

Core Competence: Maintaining performance, learning and teaching

This area is about maintaining performance and effective CPD for oneself and others, self-directed adult learning, leading clinical care and service development, participating in commissioning, quality improvement and research activity.

This means that as a GP you should:

- Understand the technical and ethical difficulties of designing research studies using bio-medical models
- Have an awareness of the evidence regarding the health needs of people with intellectual disability
- Understand the evidence regarding the effectiveness of routine health interventions, including annual health checks
- Understand the importance of developing and maintaining continuing learning of physician-based issues that are barriers to healthcare, including:
  - a lack of specialist knowledge about the health issues of people with intellectual disability
  - a lack of awareness of appropriate specialist support services (behavioural support teams or psychiatric or neurological assessment) and their availability

Core Competence: Organisational management and leadership

This is about the understanding of organisations and systems, the appropriate use of administration systems, effective record keeping and utilisation of IT for the benefit of patient care. It also includes structured care planning, using new technologies to access and deliver care and developing relevant business and financial management skills.

This means that as a GP you should:

- Understand the impact of the doctor’s working environment on the care provided to patients with intellectual disability, e.g. access, atmosphere in the waiting area, the measures taken to compensate for sensory impairment
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Core Competence: Practising holistically and promoting health

This is about the physical, psychological, socioeconomic and cultural dimensions of health. It includes considering feelings as well as thoughts, encouraging health improvement, preventative medicine, self-management and care planning with patients and carers.

This means that as a GP you should:

- Understand the impact of intellectual disability on family dynamics and the implications for physical, psychological and social morbidity in the patient’s carers
- Understand that by the time the patient with intellectual disability has reached adulthood the parents have gone through a different series of transitions to other parents and subsequently if their child dies they may go through a bereavement process that differs from those whose child without intellectual disability dies (see also 3.09 End-of-Life Care)
- Understand the emotional and sexual needs of adults with intellectual disability and how they can be expressed
- Demonstrate the use of screening tests for adults with intellectual disability to detect neurological and psychiatric problems such as dementia and depression

Core Competence: Community orientation

This is about involvement in the health of the local population. It includes understanding the need to build community engagement and resilience, family and community-based interventions, as well as the global and multi-cultural aspects of delivering evidence-based, sustainable healthcare.

This means that as a GP you should:

- Recognise the risk to adults with intellectual disability of physical, sexual, financial, institutional, discriminatory and emotional abuse
- Be aware of the sometimes negative response of the community to the presence of adults with intellectual disability, especially in the area around communal homes, such as ‘hate crimes’
- Offer consultations at times which provide optimal care of the patient by ensuring access to key workers and services
- Describe the roles of carers, respite care and voluntary and statutory agencies, and demonstrate an ability to work in partnership with these so that there is co-operation without duplication based on a free flow of communication which, when necessary and possible, maintains confidentiality
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Case discussion

Amy lives in a residential home with 40 other residents, supported by a staff some of whom are permanent and experienced and some of whom are employed by an agency for periods of weeks or months. She has moderate intellectual disability and attends a local training centre five days each week. Her parents live near the home and they visit her regularly – every other weekend she returns home and stays overnight.

She is 41 years old and the staff bring her to see you saying that recently her behaviour has changed. She is accompanied on this occasion by a carer who has looked after her for years and relates a detailed history, together with her concerns:

- Amy has become aggressive, especially at meal times. During a meal with the other residents she can lash out and hit a member of staff or someone sitting next to her
- Her appetite has decreased and there is concern she has lost weight
- Whereas before she used to be the first ready to go to the training centre every morning, she is now rarely ready and needs help with dressing before she goes
- She used to recount to her parents what she had made and done each day but now remains quiet when they visit

You ask about her general health:

- She frequently wets herself
- Her periods are no problem now – she has not had one for seven months
- Her sleep is disturbed and she wanders from her room at least once each night
- Her bowels open every day as before but she has become incontinent of faeces

Reflective questions

To help you understand how the GP curriculum can be applied to this case, ask yourself the following questions:

<table>
<thead>
<tr>
<th>Core Competence</th>
<th>Reflective Questions</th>
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<tr>
<td><strong>Fitness to practise</strong>&lt;br&gt;This concerns the development of professional values, behaviours and personal resilience and preparation for career-long development and revalidation. It includes having insight into when your own performance, conduct or health might put patients at risk, as well as taking action to protect patients.</td>
<td>Do I have any preconceptions about intellectual disability?</td>
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<td><strong>Maintaining an ethical approach</strong>&lt;br&gt;This addresses the importance of practising ethically, with integrity and a respect for diversity.</td>
<td>What does patient autonomy mean for this patient? What would be my reaction to an adult without intellectual disability who presents with the same behaviour problems?</td>
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### Communication and consultation
This is about communication with patients, the use of recognised consultation techniques, establishing patient partnerships, managing challenging consultations, third-party consulting and the use of interpreters.

What are the difficulties in obtaining a history of behaviour change in an adult with intellectual disability?

### Data gathering and interpretation
This is about interpreting the patient’s narrative, clinical record and biographical data. It also concerns the use of investigations and examination findings, plus the adoption of a proficient approach to clinical examination and procedural skills.

Who else could I ask to provide further information?

### Making decisions
This is about having a conscious, structured approach to decision-making; within the consultation and in wider areas of practice.

What is my differential diagnosis, and how would I explore it?

### Clinical management
This concerns the recognition and management of common medical conditions encountered in generalist medical care. It includes safe prescribing and medicines management approaches.

If no social cause was present, what are the alternative causes of behaviour changes?

### Managing medical complexity
This is about aspects of care beyond managing straightforward problems. It includes multi-professional management of co-morbidity and poly-pharmacy, as well as uncertainty and risk. It also covers appropriate referral, planning and organising complex care, promoting recovery and rehabilitation.

What is the legal situation of an adult with intellectual disability residing in a supported home whose parents visit at least weekly?

How does the practice co-ordinate health promotion for patients living in residential care?

### Working with colleagues and in teams
This is about working effectively with other professionals to ensure good patient care. It includes sharing information with colleagues, effective service navigation, use of team skill mix, applying leadership, management and team-working skills in real-life practice, and demonstrating flexibility with regard to career development.

Who are the other members of this patient’s care team of which I am a member?

### Maintaining performance, learning and teaching
This is about maintaining performance and effective CPD for oneself and others. This includes self-directed adult learning, leading clinical care and service development, participating in commissioning*, quality improvement and research activity.

What are the difficulties of getting research evidence about the management of patients with intellectual disability?
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<th>What does the bio-psycho-social model mean for patients with intellectual disability?</th>
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<th>What are the community resources available to this patient in my practice area?</th>
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### How to learn this area of practice

**Work-based learning**

**In primary care**

Primary care, both inside and outside the practice, is the ideal environment to learn about the care of people with intellectual disability. GP specialty trainees should take the opportunity to gain a better understanding of the practice’s patients who are looked after in partnership with the specialist team and other agencies.

**In secondary care**

As a GP trainee you should spend time during your GP training placement with your local intellectual disability specialist and attend specialist clinics to gain a better understanding of the care of patients with intellectual disability. You should also actively assist in the annual health checks.

**Self-directed learning**

The care of people with intellectual disability is an excellent subject for discussion with your GP trainer and in groups with other specialty trainees. As a GP trainee, discussing issues with patients and carers will help you gain valuable insights into the health and social care needs of those with
intellectual disability. Postgraduate deans are responsible for the training of intellectual disability specialists as well as GPs. The local deanery will have a variety of learning opportunities that specialty trainees can attend if they want to learn more.

Learning with other healthcare professionals
The care of people with intellectual disability is a multi-agency activity that involves the patient, his or her carers and professionals from health and social care. Your learning with other professionals is, therefore, very important to gain a better understanding of their roles and how best care may be delivered.

Useful learning resources

Books and publications
- Ali A and Hassiotis A. Illness in people with intellectual disabilities is common, under-diagnosed and poorly managed British Medical Journal 2008; 336: 570–1
- Cooper S-A, Melville C, Morrison J. People with intellectual disabilities. Their health needs differ and need to be recognised and met British Medical Journal 2004; 329;: 414–15
- Danielsson S, Gillberg IC, Billstedt E, Gillberg IC. Epilepsy in young adults with autism: a prospective population-based follow-up study of 120 individuals diagnosed in childhood Epilepsia 2005; 46(6):918–23
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- Kerr M. Improving the general health of people with learning disabilities Advances in Psychiatric Treatment 2004; 10: 200–6
- Lindsay P and Burgess, D. Care of patients with intellectual or learning disability: no more funding so will there be any change? British Journal of General Practice 2006; 56(523): 84
- Martin G. Support for people with learning disabilities: the role of primary care Primary Care and Community Psychiatry 2005: 10(4):133–42
- Martin G and Lindsay PJ. Dying and living with learning disability: will health checks improve the quality of life? British Journal of General Practice 2009; 59(564): 480–1
- Sir F, Smith LK, McGrother CW. Mortality in adults with moderate to profound intellectual disability: a population-based study Journal of Intellectual Disability Research 2007; 51(7); 520-527
- Straetmans JMJAA, van Schrojenstein Lantman-De Valk HMJ, Schellevis FG, Dinant G-J. Health problems of people with intellectual disabilities: the impact for general practice British Journal of General Practice 2007, 57; 64–66
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**Web resources**

**British Institute of Learning Disabilities (BILD)**

BILD aims to improve the lives of all people with an intellectual disability. [www.bild.org.uk](http://www.bild.org.uk)

**The Challenging Behaviour Foundation**

A resource on information on challenging behaviour in people with intellectual disability and resources available to support them. [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

**Down's Syndrome Association**

A useful resource on people with Down's Syndrome and support for them and their families. [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

**Down Syndrome Medical Interest Group**

This site provides information for healthcare professionals on ‘best practice' medical care for people with Down syndrome in the UK and Ireland. [www.dsmig.org.uk](http://www.dsmig.org.uk)

**Easyhealth**

This website has downloadable easy-to-read information leaflets and books about health issues for people with an intellectual disability. [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

**GMC Learning Disabilities website**

This site aims to help doctors provide better care for people with learning disabilities by identifying the issues, highlighting patient perspectives, and showing how to put GMC guidance into practice. It includes interactive learning sessions. [www.gmc-uk.org/learningdisabilities](http://www.gmc-uk.org/learningdisabilities)

**gptom**

This site has a toolkit to support GP staff to deliver the Department of Education and Skills (DES). [www.gptom.com](http://www.gptom.com)
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Improving Health and Lives

The Public Health Learning Disabilities Observatory. www.improvinghealthandlives.org.uk

Intellectual Disability

A useful learning resource for medical, nursing and other healthcare professionals, who are required
to support equal access to their services for all disabled people. www.intellectualdisability.info

Mencap

Mencap works with people with intellectual disability to fight discrimination. www.mencap.org.uk

National Autistic Society

The National Autistic Society website includes information for professionals www.autism.org.uk

Oxleas NHS Foundation Trust

Oxleas NHS Foundation Trust provides community health, mental health and intellectual disability services. See the website for downloadable health check information and resources for GPs. www.oxleas.nhs.uk/gps-referrers/learning-disability-services

Respond

An organisation that provides counselling services to people with intellectual disability who have
erperienced trauma in their lives. www.respond.org.uk/

Royal College of General Practitioners (RCGP)

The RCGP website has a specific section on intellectual disability including downloadable material to
support annual health checks. www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-
disabilities.aspx

There is also an e-GP course on Intellectual Disability, including sessions on demographic
characteristics and hidden history, access, effective communication, working with carers, sensory
issues, syndromes and pathology, epilepsy, and health checks. www.e-gp.org

Intellectual disability resources in the online learning environment (OLE) include a course on autism
in general practice http://elearning.rcgp.org.uk/

Seeability

This site provides information about vision and hearing, including eye and hearing checks, and
promotes positive lifestyles for people with intellectual disability. www.seeability.org

Signpost Sheffield

A PCT information website about the Joint Learning Disabilities Service in Sheffield, designed for
service users, families, carers and staff. This website has a downloadable GP resource pack for health
checks. https://signpostsheffield.sheffield.gov.uk
Society for the Study of Behavioural Phenotypes

This is a useful site for the non-specialist when encountering a patient with a rare syndrome. www.ssbp.org.uk