This module is suitable for use by community pharmacists as part of their Continuing Professional Development. After reading this module, in the magazine or online, complete the post-test on our website at www.pharmacynewsireland.com and include in your personal CPD ePorfolio.

AUTHOR BIO: Bernadette Flood is a pharmacist with experience in a wide range of hospital pharmacy settings in Ireland. For the past 20 years she has provided pharmaceutical care for people ageing with intellectual disabilities living in long term residential care. This experience has awakened her interest in vulnerable populations, human rights, ethics, and quality person centred care. She was awarded a PhD by the School of Pharmacy in TCD in 2016.

People with Intellectual Disabilities and COVID-19

One pharmacist's perspective

Reflection - Is this area relevant to my practice? What is your existing knowledge of the subject area? Can you identify any knowledge gaps in the topic area?

Planning - Will this article satisfy those knowledge gaps or will more reading be required? What resources are available?

Action - After reading the article complete the summary questions at www.pharmacynewsireland.com/cpdtraining and record your learning for future use and assessment in your personal log.

Evaluation - How will you put your learning into practice?

Have I identified further learning needs?

Published by IPN.
Copies can be downloaded from www.irishpharmacytraining.ie

60 Second Summary

People with intellectual disabilities (PWID) are a vulnerable population group due to the prevalence of co-morbid physical and mental health difficulties, sensory issues, behaviour problems, poor health literacy and long-term conditions that they may experience.

Many PWID are not able to verbally report their symptoms of COVID-19 e.g. the typical symptoms of fever and breathlessness. Changes in appetite, diarrhoea, and other gastrointestinal symptoms, as well as behavioural changes may be atypical symptoms PWID present with.

Pharmacists should be aware that PWID are at greater risk of infection because of the higher prevalence of comorbid health problems and personal habits. They often live in communal settings in the community or in in-patient services.

During the COVID-19 pandemic, it is expected that some aspects of healthcare may need to be delivered by remote technology. G.P.s and psychiatrists and members of the MDT may not be in a position to attend in person due to public health advice. One obvious advantage of 'telehealth' and/or 'remote consultation' is that it will decrease the risk of communicable diseases which are transmitted by person-to-person contact.

Pharmacists should be aware that direct support staff and family members supporting PWID are the most important people in their lives. During the COVID-19 crisis residential and supported living environments are likely to be under pressure on account of staff shortages due to illness or the need to self-isolate.

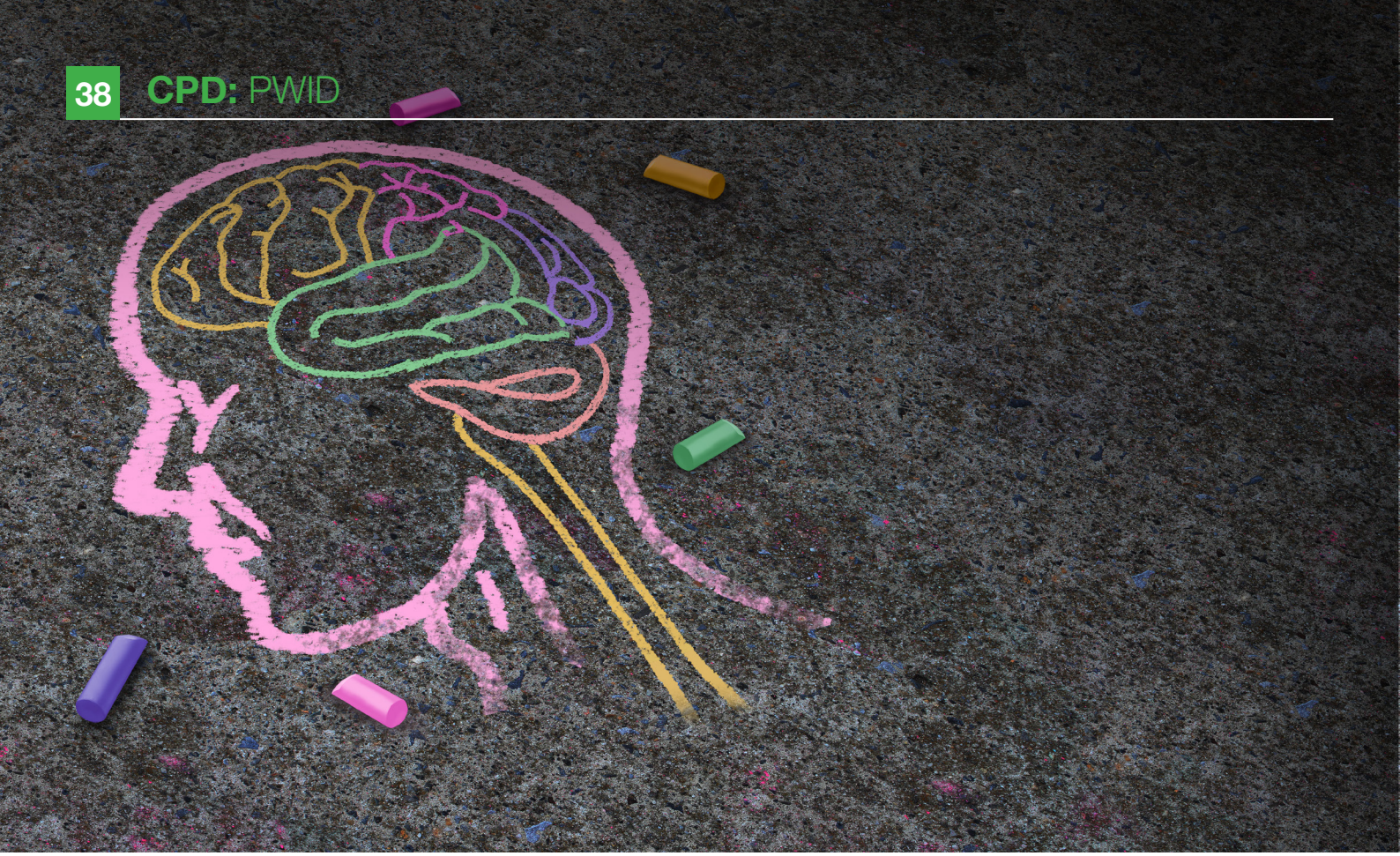
The Covid-19 pandemic presents challenges in the delivery of care to people with intellectual disabilities (ID) by pharmacists and other professional groups. People with intellectual disabilities (PWID) are a vulnerable population group[i] due to the prevalence of co-morbid physical and mental health difficulties, sensory issues, behaviour problems, poor health literacy and long-term conditions that they may experience. They are likely to have frequent contact with family members (who may be older people), carers, support staff, and people in the community. This will increase their risk of contact with people infected with the virus. Many PWID who live at home are living with ageing parent carers, who themselves are a high-risk group when it comes to COVID-19. PWID may not understand why visiting restrictions are in place, increasing their sense of social isolation and distress.

Many PWID are not able to verbally report their symptoms of COVID-19 e.g. the typical symptoms of fever and breathlessness. Changes in appetite, diarrhoea, and other gastrointestinal symptoms, as well as behavioural changes may be atypical symptoms PWID present with. Direct care staff and family members should know how to recognise, document and alert healthcare professionals, including pharmacists of such symptoms as early as possible[ii]. There will need to be sensitive yet close monitoring and support for PWID showing any symptoms.

Like everyone else, most PWID who get COVID-19 will develop mild symptoms and will recover, some unfortunately will not and will die. The risk factors for poorer outcomes and mortality are the same for everyone: underlying multi-morbidity is the key concern in the general and the ID population. Many PWID have multiple health concerns[iii], particularly pre-existing cardiovascular disease, diabetes and respiratory problems and are likely to have poorer experiences following transfer to an acute hospital setting[iv]. The added risk factors in terms of high levels of multi-morbidity in the ID population mean we need a heightened focus on prevention.

Pharmacists should be aware that PWID are at greater risk of infection because of the higher prevalence of comorbid health problems and personal habits. They often live in communal settings in the community or in in-patient services. Many PWID live in long term care settings in close proximity to other people and may not have control over a range of social contacts because of the level of support they require. Pharmacists have a role in making families and carers aware of the risks to the person with ID and highlighting reduction techniques where possible[v].

COVID-19 has resulted in recent changes in clinical practice by medical practitioners and others. The current advice to reduce social and physical contact will have a direct effect on the delivery of clinical care by members of



the multidisciplinary team (MDT) where clinical reviews often require the clinician to physically meet the person with ID. To implement social distancing effectively, MDT members will now need to consider what contacts are necessary for the tasks and to achieve specific clinical outcomes. Clinicians will consider alternatives to 'face to face' meetings in order to reduce physical contact as part of clinical assessment or review. Services and pharmacists have to support PWID and staff members who develop the infection in order to reduce the risk of spread.

Remote Clinical Prescribing and Consultation

Communication is likely the most important complex, nontechnical skill in medicine. During the COVID-19 pandemic, it is expected that some aspects of healthcare may need to be delivered by remote technology. G.P.s and psychiatrists and members of the MDT may not be in a position to attend in person due to public health advice. One obvious advantage of 'telehealth'[vi] and/or 'remote consultation' is that it will decrease the risk of communicable diseases which are transmitted by person-to-person contact.

The importance of clear communication between patient, direct care staff, nurse, Remote Clinical Team, G.P., psychiatrist, pharmacist, MDT and other staff is recognised. The standards expected of all personnel apply equally to digital and conventional consultation and healthcare settings. Safety-netting advice is crucial because some patients deteriorate in week 2, most commonly with pneumonia.

The Royal College of Psychiatrists has identified six Cs (competence, communication, contingencies, confidentiality, consent and confidence) and three Ss (summarise, safety net and schedule follow up) of remote consulting that will be helpful to pharmacists and others engaged in this process https://www.rcpsych.ac.uk/about-us/responding-to-covid-19/responding-to-covid-19-guidance-for-clinicians/digital-covid-19-guidance-for-clinicians .

Support Services and Staff

Pharmacists should be aware that direct support staff and family members supporting PWID are the most important people in their lives. During the COVID-19 crisis residential and supported living environments are likely to be under pressure on account of staff shortages due to illness or the need to self-isolate. Staffing levels will be stressed with the potential for placements to break down at short notice. Pharmacists should work with MDT members and direct support staff to maintain PWID in their home environments where the medication related risks to their care can be managed effectively. Choking episodes are relatively specific to the population of people in disability services[viii] and this risk may increase when PWID are not supported by support staff or family members who are familiar with their medication administration needs and the various risks that may exist. Day services may be closed and this increases pressure on support staff and families when supporting PWID. Extra supports and expert advice will likely be required for an indefinite period of time.

There may be increased risk of the following particular safety issues for PWID occurring during the pandemic-

- Diagnostic overshadowing i.e. where staff can attribute all aspects of care to the intellectual disability e.g. failing to consider the potential contribution of medication side effects to a change in behaviour.
- Healthcare by proxy i.e. PWID are very dependent on those providing direct care (e.g. unregulated non nursing staff) for access to healthcare
- Staff competence to access and respond to changing clinical profile of vulnerable PWID including medication related side effects and risk of choking.

Pharmacists should be aware of staff related threats to medication safety for PWID

- miscommunication among health care provider/s
- drug information that is not accessible or up to date
- confusing directions and/or labelling
- poor administration technique
- being unfamiliar with the patient
- lack of drug knowledge
- incomplete patient medication history
- lack of redundant safety checks*

- lack of awareness of any particular individual patient risk factors e.g. pureed diet
- lack of evidence-based protocols, and
- staff assuming roles for which they are not prepared.

**Redundancy in healthcare implies that healthcare organisations have established multiple procedures or technologies to independently arrive at similar outcomes, in order to double check or ensure that routines and activities are conducted appropriately and to detect errors in their implementation*[ix].

Children's Services

Children and young people with ID are especially vulnerable to infection and to changes in their care. Special schools are closed causing confusion for families and schools and hence young PWID themselves. COVID-19 illness and isolation among education professionals will carry their own risks in delivering safe education. Disruption to the routines of children and young PWID and/or autism spectrum disorder can lead to significant increases in distressed behaviours. Changes in routines are inevitable at this time and may come from changes in the education setting, children being at home for prolonged periods, parent/carer health problems, and changes in other support services secondary to illness.

Anxiety related to coronavirus and an increase in health-related anxiety in young people and their families/carers is likely.

Mental Health Support

The impact of the pandemic on the mental health of PWID and their families and support staff is uncertain at present. Restriction in regular activities and the concerns of family members and support staff could impact upon the mental health of PWID leading to evidence of mental health difficulties (e.g. anxiety and depression) and changes in behaviour. It will be important for pharmacists to be alert to the signs of distress in patients with ID and in support staff, and families. More frequent contact by the MDT members may be required to help people to remain well along with clinical interventions.

PWID often use psychotropic medication and there are initiatives to ensure rational use of these valuable medications[x]. Prescribing and de-prescribing of medication for an individual with ID is a complex process. It is important that pharmacists support optimisation of all physical and mental health medications during the medication use process.

Family members, support staff and PWID may seek drug therapy to help them support PWID experiencing distress secondary to COVID-19 restrictions. Clinicians should rationally review all requests for additional medication. Medical practitioners, pharmacists and MDT members should consider the context in which the person with ID is living and the changes that may have occurred in their support/care plans because of the impact of COVID-19 on their environment including their familiar support staff. Where additional medication is prescribed, regular medication review by the authorising psychiatrist and/or general practitioners is essential, supported by MDT and pharmacy input.

> **"the health and disability sectors are not adequately prepared and equipped to meet the needs of people with intellectual disabilities."**
>
> **Professor Mary McCarron**

Critical Care for PWID

PWID in hospital or in-patient care services are among the most vulnerable patients because of their need for high-level clinical care and support from people who are familiar with them. Supporting PWID in-patient units to engage with treatment and recovery when restrictions on social contact are in place is challenging to hospital and in-patient staff. Pharmacists in hospitals have a role in ensuring safety for PWID in the medication use process[xii].

Where admission to a general hospital or critical care is required, support may be required for that person and their family to understand and manage the process.

Some guidelines on critical care suggests frailty as a metric to guide access to treatment. Frailty scales may not be validated in population with ID and if used inappropriately may disadvantage the person with ID. Each person with ID should be assessed individually. Many PWID will need help with activities of daily living but this does not mean that they can't recover from a virus. The difficulties and challenges of caring for PWID should not be magnified and the safety net of reasonable adjustments must be retained in this vulnerable population group. The circumstances surrounding COVID-19 illness, care, and death of a PWID will have a prolonged and significant impact on family and staff caregivers.

Conclusion

Professor Mary McCarron, lead investigator on the Intellectual Disability supplement to TILDA (IDS-TILDA) has pointed out that the health and disability sectors *"are not adequately prepared and equipped to meet the needs of people with intellectual disabilities"*[xiii]. In the past, this group has been subjected to *"attitudinal bias and prejudice that has devalued their lives and reduced their timely access to appropriate healthcare."* Prof McCarron[xiv] has advocated for the relevant skills to be in place in healthcare and social care systems, in order to ensure that they can respond in the right way to those with ID.

COVID-19 has placed increased pressure on all areas of healthcare in Ireland and internationally. Pharmacy has a pivotal role to play in adapting our health and social services to meet this challenge, for the benefit of patients, PWID, family members and society. The relevance of 'specialist' pharmacists[xv] with insight into the complexity of healthcare and medication needs of the population with ID must be made apparent. Emily O'Reilly, the former Ombudsman has remarked *'We all have a duty to make the public aware of what our contribution is'*.

Pharmacy must prioritise the vulnerable in society and ensure equal outcomes for PWID. The limited evidence available in the literature suggests that pharmacists can make positive interventions in relation to the quality of the medication use process, in collaboration with other healthcare professionals, carers and patients with ID.

The following three principles will inform best practise by pharmacists in the care of the population with ID

1. The needs of PWID during the medication use process are greater and more complex and often present differently from those of the general population.

2. PWID are more likely to have impaired communication and therefore require special attention from pharmacists and others.

3. PWID have the right to access pharmaceutical care and health services and they should be provided within current legislative and professional frameworks.

References

i: https://www.rcpsych.ac.uk/docs/default-source/members/faculties/intellectual-disability/covid-19-facultypsychid.pdf?sfvrsn=86f6a7da_2

ii: https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff

iii: Cooper, S., 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 16, 110 (2015). https://doi.org/10.1186/s12875-015-0329-3

iv: Iacono T, Bigby C, Unsworth C, Douglas J, Fitzpatrick P. A systematic review of hospital experiences of people with intellectual disability. BMC Health Serv Res. 2014;14:505. Published 2014 Oct 25. doi:10.1186/s12913-014-0505-5 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4210514/

v: HSE. Coronavirus: Protect yourself and others https://www2.hse.ie/coronavirus/

vi: T Smith AC, Thomas E, Snoswell CL, et al. Telehealth for global emergencies: Implications for coronavirus disease 2019 (COVID-19) [published online ahead of print, 2020 Mar 20]. J Telemed Telecare. 2020; https://pubmed.ncbi.nlm.nih.gov/32196391/

vii: Royal College of Psychiatrists 2020. COVID 19 and remote consultations. https://www.rcpsych.ac.uk/about-us/responding-to-covid-19/responding-to-covid-19-guidance-for-clinicians/digital-covid-19-guidance-for-clinicians

viii: NTMA and State Claims Agency, National Clinical Incidents, Claims and Costs Report. 2015 Smith et al. https://stateclaims.ie/uploads/publications/State-Claims-Agency-National-Clinical-Incidents-Claims-and-Costs-Report.pdf

ix: Handbook of Human Factors and Ergonomics in Health Care and Patient Safety, 2016 edited by Pascale Carayon 12.7.2. Redundancy Page 180. https://www.google.com/search?q=handbook+of+human+factors+and+ergonomics+in+health+care+and+patient+safety&rlz=1C1GCEV_en&oq=Handbook+of+Human+Factors+and+Ergonomics+in+Health+Care+and+Patient+Safety&aqs=chrome.0.0j46j0j69i60l2.2146j0j7&sourceid=chrome&ie=UTF-8

x: https://www.nationalelfservice.net/treatment/antipsychotics/psychotropic-medication-finding-ways-forward-for-adults-with-intellectual-disabilities-rsmpsychotropics/

xi: Flood, Bernadette. De-Prescribing of Psychotropic Medications in the Adult Population with Intellectual Disabilities: A Commentary. Pharmacy 2018, 6(2), 28; https://doi.org/10.3390/pharmacy6020028

xii: Flood B. Safety of People with Intellectual Disabilities in Hospital. What Can the Hospital Pharmacist Do to Improve Quality of Care?. Pharmacy (Basel). 2017;5(3):44. Published 2017 Aug 4. https://pubmed.ncbi.nlm.nih.gov/28970456/

xiii: http://www.irishhealth.com/article.html?id=27072 COVID-19 and intellectual disabilities Particularly vulnerable group

xiv: https://www.tcd.ie/news_events/articles/timely-and-appropriate-covid-19-care-urgent-for-people-with-an-intellectual-disability/

xv: Flood, Bernadette 2016. The Specialist Pharmacist and Quality Indicators for Medication Use in People with Intellectual Disabilities and Behaviour Disorders. Thesis, TCD. http://www.tara.tcd.ie/bitstream/handle/2262/83126/Flood%2C%20Bernadette_PhD%20Thesis%2029.08.16.pdf?sequence=1&isAllowed=y

xvi: O'Dwyer, M., A. Mestrovic, and M. Henman, Pharmacists' medicines-related interventions for people with intellectual disabilities: a narrative review. Int J Clin Pharm, 2015. 37(4): p. 566-78 https://www.ncbi.nlm.nih.gov/pubmed/25903938