WHEN PUSH COMES TO SHOVE

Managing Challenging Dementia-Related Behaviours Without Drugs

Dementia is commonly associated with cognitive impairment, particularly memory decline. However, dementia not only affects an individual's ability to think and remember, it also causes changes in personality, emotions, and behaviour. These non-cognitive changes are collectively referred to as behavioural and psychological symptoms of dementia (BPSD). Examples of BPSD include depression, anxiety, delusions, hallucinations, decreased

inhibition, and agitation, as well as physical and verbal aggression.

Nearly all individuals with dementia will experience at least one behavioural or psychological symptom at some point during the course of the disease. Which of these symptoms are experienced, when, and for how long varies for each person.

Often, the behavioural and psychological symptoms of dementia are more challenging for caregivers to handle than the cognitive decline. Agitation and aggression can be especially challenging and, in some cases, can result in dangerous situations for the person with dementia and/or his or her caregiver.

Antipsychotic drugs are commonly used to manage challenging BPSD. They are a tempting treatment option because it is relatively quick and easy to give someone medication, and the desire is understandably strong to find a solution that will curb challenging behaviours. However, research has consistently demonstrated that antipsychotics are not particularly effective for addressing BPSD, and their use comes with a high level of risk.

In fact, the risks are considered so significant that the United States Food and Drug Administration (FDA) requires that all types of antipsychotic drugs contain a black box warning, highlighting the higher risk of death if the drugs are used by individuals with dementia. This black box warning requirement has been in effect for atypical antipsychotics since 2005, and for conventional (or typical) antipsychotics since 2008.

RISK OF MORTALITY IS NOT THE ONLY SIGNIFICANT SIDE EFFECT EXPERIENCED BY INDIVIDUALS WITH DEMENTIA WHO USE ANTIPSYCHOTICS.

Other potential side effects include increased risk of falls, heart disease, pneumonia, diabetes, and movement disorders. Use of antipsychotics has also been associated with increased risk of cognitive decline.

Despite all of the evidence of little benefit and the great potential for harm, and despite recommendations that individuals with dementia should avoid antipsychotics, except in cases of severe aggression or agitation, these drugs continue to be widely prescribed for dementia patients. A recent review and meta-analysis conducted by Dr. Stephen Ralph and Dr. Anthony Espinet – published in *Journal of Alzheimer's Disease Reports* in 2018 – found that inappropriate prescribing of antipsychotics continues to be common, with some countries seeing little to no change in use over the past decade or, in many cases, usage has increased notwithstanding all warnings to the contrary.

Ten years ago, the Banerjee report established that inappropriate prescribing of antipsychotics in the elderly was occurring in the U.K. and such patients had an 85% increased risk of adverse events and greater mortality. "The Banerjee report found that of the 180,000 antipsychotic prescriptions for people with dementia reviewed in the study, 140,000 were considered inappropriate," noted Dr. Ralph, associate professor at the School of Medical Science, Griffith University in Australia. "Our research revealed that many significant studies worldwide since the Banerjee Report have further contributed to the evidence of adverse impacts of use of antipsychotic drugs in dementia." According to Dr. Ralph and Dr. Espinet, the recent literature is consistent: there is an increased risk of all-cause mortality associated with dementia or other patients when prescribed the antipsychotic drugs. Accordingly, prescribing antipsychotic drugs for dementia or for other mental health care should be avoided and alternative means should be sought for handling behavioural disorders of such patients.

ALTERNATIVES FOR ADDRESSING BPSD

There are a multitude of non-drug interventions that may help with BPSD. So many, in fact, that it can be difficult for caregivers to figure out what to try, as well as to keep track of what does and does not work. One team of experts has developed an approach to help caregivers detect BPSD, consider possible →

TYPES OF ANTIPSYCHOTICS

Antipsychotic medications are classified into two sub-groups: (1) Conventional, or typical; and (2) atypical. Conventional/typical antipsychotics were the first generation of this type of drug, developed in the mid-1950s. Examples include Haldol and Loxitane. The second generation of antipsychotic medications – atypical – were developed in the 1980s. Examples include Abilify and Risperdal.

A black box warning is the most serious type of warning placed on medication, and is used when there is reasonable evidence of a serious hazard.

The U.K.-based Banerjee Report provided international leadership on the topic of treatment and practices for dementia patients, with an aim to reduce prescribing antipsychotic drugs.

causes, and discover optimal treatments in a systematic way. They call the approach DICE – an acronym that captures the four steps of the process: describe, investigate, create, and evaluate.

"We designed DICE to be used by any health professional and, over the course of working with family caregivers over the past few years, we realized that the approach was easily adaptable for their use in the home, or for staff caregivers in facilities," explained Dr. Helen Kales, the lead researcher on the DICE Approach, and head of the University of Michigan Program for Positive Aging. "Family members are easily able to identify and describe new symptoms; look for what factors in the person with dementia, caregiver, or environment might be associated with BPSD; implement some of the interventions; and assess how well various interventions are working. In many cases, family caregivers may be the ones that make the health professionals aware of the DICE Approach, and encourage its use."

The DICE Approach, which aims to help caregivers manage BPSD, was developed in 2011 by experts from the University of Michigan Program for Positive Aging, the Johns Hopkins Alzheimer's Disease Research Center and Center for Innovative Care in Aging.

THE FOUR STEPS OF THE DICE APPROACH

STEP 1 DESCRIBE

The goal of the first step is to collect a thorough description of the problematic behaviour. For instance, in what context is the behaviour occurring (i.e. who, what, when, and where), what is the degree of distress to the patient and caregiver, and what is the social and physical environment. At this stage, caregivers should also think about possible triggers of the behaviour.

STEP 2 INVESTIGATE

In the second step, the health care provider searches for any potential underlying, modifiable causes for the challenging behaviour. "BPSD seem to be a consequence of multiple, interacting factors related to the patient, caregiver, and environment," explained Dr. Kales. "All three types of factors are considered in the investigate step." For instance, a challenging behaviour might be caused by undiagnosed medical conditions or untreated pain (factors related to the patient), ineffective communication style (caregiver factor), or overstimulation or lack of activity/structure (environmental factors).

STEP 3 CREATE

The third step involves the health care team, family caregivers, and the individual with dementia (if possible) collaborating to create and implement a treatment plan. The contents of this plan will depend on what was discovered in the previous steps. Of course, a top priority should be addressing any physical problems that were detected. For instance, this might involve treatment for a urinary tract infection, constipation, or dehydration. Other medical interventions might include stopping drugs with behavioural side effects, managing pain, and addressing any hearing and vision impairments.

Behavioural and environmental approaches should also be considered. While there are several strategies that may be effective depending on the particular situation, the following five generalized strategies are often a good place to start when seeking to address BPSD through non-pharmacological means:

- Providing caregiver education and support (for instance, learning about the various stages of dementia and what are realistic expectations at each stage);
- Enhancing communication between caregivers and the person with dementia (for instance, using reassuring and calming tones, as opposed to using negative or confrontational language);
- Creating meaningful activities for the person with dementia (for instance, if an individual enjoyed fishing but is no longer able to do so, then meaningful activities might include sorting a tackle box without hooks, watching a fishing video, or looking through a fishing magazine);
- Simplifying tasks and establishing structured routines; and
- Ensuring that the individual's surroundings are safe, and increasing or decreasing stimulation in the environment.

Antipsychotic medication may be part of a DICE treatment plan as well, but only when there is the potential for the individual with dementia or caregivers to be harmed by the behaviour, or as a last resort when other interventions have not worked.

STEP 4 EVALUATE

The fourth step involves assessing whether the treatment plan was implemented effectively, whether the target symptom improved, whether the caregiver's stress was reduced, and whether there were any unintended effects. "If antipsychotic drugs were used, it is important to consider reducing the dose or discontinuing use at this stage," emphasized Dr. Kales. "The drug may no longer be needed, given that behaviours change and fluctuate throughout the course of dementia."

Once a challenging symptom has been effectively addressed, caregivers will continue to look for new behaviours and use the DICE process again as needed.

RESEARCH HAS SHOWN THAT OVER TIME CAREGIVERS CAN LEARN WHAT TRIGGERS SYMPTOMS IN THE INDIVIDUAL WITH DEMENTIA AND OFTEN CAREGIVERS BECOME ADEPT AT NOTICING AND ADDRESSING THE TRIGGERS BEFORE SYMPTOMS FULLY DEVELOP.

"I'm really excited that the DICE Approach is now being promoted for widespread use through a new manual and training website," said Dr. Kales. "The more caregivers that discover and use DICE, the better, because our research has shown that the approach helps both the person with dementia and the caregivers themselves by helping to decrease their distress over BPSD. And when it comes to dealing with challenging behaviours associated with dementia, caregivers really need the help."

Another key resource that can help family caregivers deal with challenging BPSD is a book entitled *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss*. This book, written by Nancy Pace and Dr. Peter Rabins, provides useful information about all aspects of caring for someone with dementia, including a section that describes the "six Rs" for managing challenging behaviours (restrict, reassess, reconsider, rechannel, reassure, and review).

THE SIX RS

Restrict:
If an individual with dementia is experiencing challenging behaviour, the first thing a caregiver should do is to attempt to calmly halt the behaviour, particularly if the behaviour is potentially harmful to the person or to others. Sometimes, however, trying to restrict or stop the behaviour may upset the person even more.

Reassess:
This strategy involves considering the underlying causes or triggers of a particular behaviour. For instance, it could be a medical issue, such as joint or gut pain, or it could be fatigue or a reaction to medicine.

A manual and training website about the DICE Approach launched earlier this year. The manual, *The DICE Approach: Guiding the Caregiver in Managing the Behavioral Symptoms of Dementia*, is available for US$29.99 on amazon.com. The DICE website (www.programforpositiveaging.org/dice-approach) is a training course, where caregivers learn in detail over a series of modules how to use the DICE Approach. The training course includes electronic simulations for caregivers to practice what they have learned with realistic cases. Access to the website costs US$69.99 for one year of access and includes the manual, as well as a downloadable DICE worksheet for caregivers to use. Group rates are available for facilities that want to train their staff using the website and manual. Interested facilities should contact the Program for Positive Aging for pricing.

Reconsider:
Caregivers are encouraged to imagine the situation from the point of view of the individual with dementia, which cultivates empathy and can ease the stress on both parties.

Rechannel:
This strategy involves directing or steering the individual with dementia away from challenging behaviours to safe, non-destructive activities.

Reassure:
The caregiver should take time to comfort and support the individual with dementia when he or she is upset, anxious, or afraid.

Review:
Once a challenging behaviour has transpired, and the individual has been redirected, the caregiver should consider the effectiveness of the various techniques applied (and what worked and what did not), and come up with strategies to try next time.

The book contains numerous scenarios to help caregivers apply the concepts described. One of the key messages in the book is that challenging behavioural and psychological symptoms are the result of damage to the brain. While it can be easy to accept that memory and thinking problems are caused by dementia, it can be difficult for caregivers to understand that their loved ones' outbursts, argumentativeness, and stubbornness are also because of the disease. These upsetting behaviours are rarely deliberate and, although challenging, it is important to not take the behaviour personally.