# **Understanding the PERSON with dementia (Chapter 1)**

Introducing what is dementia.

We are facing a global challenge with the fast-rising prevalence of the condition of dementia. The mislabelling of the condition requires our reflection and support to remove all its bad tags. Being able to recognize the warning signs of dementia also helps people seek early intervention.

何謂認知障礙症。

我們正面臨全球認知障礙症急速增長的挑戰,社會上對於這症狀的錯誤標籤需要我們去反映和正視,以協助公眾去除有關的負面標籤。再者,能夠讓患者辨識認知障礙症的早期徵兆,往往可幫助他們及早求診。

Dementia is the greatest global challenge for health and social care in the 21st century. The main risk factor for dementia is age, with the prevalence increasing exponentially for people over 60 years of age. The incidence of all types of dementia at age 65 is approximately 2% with rates doubling approximately every 5 years, resulting in 20–40% of adults in their 80s–90s being affected. In Hong Kong, the estimated number of people with dementia was 103,433 among those aged 60 years or above in 2009. This number is projected to increase by 222% to 332,688 by 2039. It is estimated that more than 50% of long-term care residents are affected by dementia.

認知障礙症是21世紀全球醫療和社會保健面臨最嚴峻的考驗。年齡是認知障礙症最主要的因素,隨著年紀增長,到了60歲以上的患者人數會極速增長。在65歲時,各種認知障礙症的發病率約為2%,隨後每五年以雙倍速度增長,到了80-90多歲時,約有20-40%人受到影響。在2009年,香港60歲以上患有認知障礙症人士約103,433人,這數字到了2039年,預計會大幅增加222%至332,688人。預計超過50%住在需要長期照顧院舍的人受到認知障礙症的困擾。

This figure is a conservative estimate as dementia is often unrecognized or under-reported. As stated by the World Health Organization (2012), the rate of diagnosis is accelerating with 7.7 million new cases identified each year. Although most people with dementia live in the community, approximately 20% of general hospital inpatient beds are at any time occupied by patients with dementia. So, are health care providers or hospitals adequately prepared to care for this group of people?

這是一個保守的約數,因為認知障礙症往往不易發現和有漏報情況。根據 2012 年<u>世界衞生組織</u>的報告,確診的速度正在加快,每年約有 770 萬新症被確診。雖然大部分患者均居於社區,但約有兩成普通科醫院病床被認知障礙症病人使用。這樣來說,醫護人員或醫院服務是否已經充分準備好照顧此類患者?

#### What is dementia?

Dementia is defined as a chronic and progressive decline in cognitive ability that interferes with daily functioning. However, dementia is not a disease, but a collection of many symptoms that suggest the presence of a brain disorder. It is mostly neurodegenerative in nature.

其麼是認知障礙症?

<u>認知障礙症</u>是指認知功能長期逐步減退,並影響到日常生活的自理能力。然而,這並不是一種疾病,而是很多不同徵狀顯示出腦部機能失調,大部分為腦部神經組織退化。

#### The mislabelling of dementia

The term "dementia" originates from the Latin word demens, originally meaning "madness"



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from *de-* "without" men, i.e., senseless or "being out of one's mind". It was taken to mean all kinds of mental disease before it was first used in the modern sense by the French psychiatrist Pinel. From *Roget's Thesaurus*, it carries the synonyms brainsickness, craziness, insaneness, insanity, lunacy, madness, mental illness, psychopathy, and unbalance.

認知障礙症被錯貼標籤

認知障礙症的英語名稱"Dementia"一詞,來自拉丁語的"Demens",原指「瘋狂」(de-指「沒有」-mens指「心智」,代表沒有意識或「失心瘋」)。這一詞以往泛指一切的精神病,直至由法國精神科醫生皮內爾(Pinel)首次把此症狀定義為現代我們所認識的認知障礙症。在Roget's同義詞詞典中,此詞的同義詞包括精神錯亂、瘋狂、精神失常、荒誕、精神病、心理變態、心理不平衡等。

Despite an improved public awareness of dementia, a lack of understanding of dementia adds to fears and to its stigmatization. This can lead those who are living with dementia, both the person and their family, to delays in seeking diagnosis and help. The negative perceptions, and labelling of persons with dementia contribute to the development of a cycle of mutual distress. Some may consider these symptoms as normal ageing. Not only does the person with dementia have "problems" that continue to go unresolved, compromising their quality of life, but caregivers also suffer from feelings of frustration, incompetence, anger, and resentment. Those feelings, perceptions, and labels contribute to a downward spiral in care.

儘管公眾對認知障礙症的關注已有所改善,但對於此症的誤解,加深了大眾對它的恐懼和 污名化,這令患者及其家屬延誤了求診和求助的時間。這些負面的印象,及對認知障礙症 患者的標籤,形成了相互窘迫的循環。有些人把這些徵狀當成正常老化的現象,結果不單 止患者不能解決他們身體出現的「問題」,犧牲其生活質素,照顧者也同樣受到焦慮、無 助、憤怒和怨恨的煎熬。這些感受、觀念和標籤,令照顧的過程形成惡性循環。

To help eliminate negative labels that stigmatize, unfairly categorize, and reduce the quality of care for people with dementia, we hope that you, as a caregiver, whether formal or informal, will think carefully about the words and labels used, as well as the risk of generalized negative labels about the behaviour, to the person with dementia. Therefore, do not just refer to the person as "confused" or "demented".

我們希望作為正式或非正式照顧者的你們都可以多想一步,小心遣詞用字,留意對患者行為貼上負面標籤的風險,幫助消除這些負面標籤及污名化,引起不正當的歸類和減低對認知障礙症患者的護理質素。因此,不要只形容某人「錯亂」或「痴呆」。

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There are a few Core Principles for supporting people with dementia that we will walk through in this course.

支援認知障礙症患者有幾個重要原則,我們將在此課程內逐一闡述。

- 1. Know the early signs of dementia 瞭解認知障礙症的早期徵狀
- 2. Recognize and respond to the signs of distress resulting from confusion experienced by the person

分辨及回應患者因生活上的混亂而出現的憂慮徵兆

- 3. Promote independence and encourage activity 提升獨立自理和鼓勵參與活動
- 4. Communicate sensitively to support meaningful interaction 謹慎地溝通,以提供有意義的交流互動
- 5. Family members and other caregivers are valued, respected, and supported 重視、尊重和支持家庭成員和其他照顧者
- 6. Managers are responsible for ensuring that staff are trained and well supported to meet the needs of people with dementia

經理須確保員工均受過訓練,能夠支援認知障礙者的需要

### Knowing the early signs of dementia

Signs and symptoms of dementia include changes to memory, reasoning and judgement, language and communication abilities, mood and behaviour, problem-solving ability, and orientation. The sad thing is that the condition may affect a person's ability to work, live independently, and manage relationships.

瞭解認知障礙症的早期徵狀

認知障礙症的徵兆和症狀包括記憶、推斷思考與判斷力、語言與溝通能力、情緒與行為、解決問題能力和環境定向判斷力的改變,遺憾的是,情況可能會影響一個人的工作、獨立 生活和處理關係的能力。

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Clinical presentations of dementia can differ depending on the disease causing it. Often it would be the family members or close friends who notice changes in certain areas of cognition and functioning of the person. If a person has mild cognitive impairment (MCI), he/she may have minor difficulties with memory and attention, and some language issues. Yet, the changes are not severe enough to interfere with daily life or independent function. MCI does not always lead to dementia. However, you need to see a doctor if you are worried and thinking it is progressing to become dementia. Therefore, the informant history is important. Dementia screening tests can help early detection. Screening tests such as the AD8 is an 8-question interview tool that distinguishes individuals with very mild dementia from those without dementia. It is sensitive to detecting early cognitive changes associated with many common dementing illnesses. However, screening tests are insufficient for diagnosing dementia.

## So when and what make us suspicious?

認知障礙症的臨床症狀,會因為不同疾病引發而異。往往也是家人或密友發現到某人在認知和生活運作上的某些地方出現改變。如一個人有輕度認知障礙(MCI),那人可能會對記憶和專注力,和某些語言表達上顯得有輕微困難。然而,那些改變並不會嚴重到會影響日常生活或獨立自主,MCI並不一定會導至認知障礙症。但假如你擔心或懷疑這些徵狀正在進一步發展成認知障礙症,則需要求醫。因此,患者身旁親友等提供的病史叙述就很重要。認知障礙症篩選測試可助提早發現病情。如AD8等篩選測試,以8條問題辨別非常輕微或全無認知障症的受訪者。測試工具能很敏銳地檢測出早期認知改變;儘管如此,篩選測試本身並不足以診斷出認知障礙症。

那麼,甚麼時候和甚麼才會令我們起疑?

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### The key symptoms of dementia include:

認知障礙症的主要徵狀包括:

- 1. Memory loss that disrupts daily life, e.g., trouble remembering appointments 記憶力下降以致影響日常生活,例如難以記起已定下的約會
- 2. Challenges in planning or solving problems 計劃或解決問題時出現困難
- 3. Difficulty performing familiar tasks at home, at work, or at leisure 在家裡、工作上或休閒時做熟悉的事也感到困難
- 4. Disorientation to time and place e.g. forgetting correct month or year 對於時間和地點覺得迷惘,例如忘記了正確的月份或年份
- 5. Trouble understanding visual images and spatial relationships 對於理解圖像和空間的關係顯得有困難
- 6. Misplacing things and losing the ability to retrace steps 把東西錯放或忘記了原來的位置,喪失回溯原路的能力
- 7. Impaired or poor judgment e.g. problems making decision, bad financial decisions 判斷障礙或失誤,例如不能做決定、作不良財務決定等
- 8. Withdrawal from work or social activities 退出工作或社交活動
- 9. Changes in mood and personality 情緒和性格改變
- 10. Loss of initiative 失去主動性

#### Differentiating delirium and depression

It is important to recognize that cognitive impairment or dementia is a syndrome that could be caused by many different disorders, which, at least in some cases, may be reversible if the correct diagnosis of the cause is made and treated. Cognitive impairment that imitates dementia may be associated with delirium or depression.

與譫妄症和抑鬱症的分別

此外,我們須要知道,認知缺損或認知障礙症是一種由很多不同機能失調導致的綜合症狀,當中至少有部分症狀,若及時得到正確診斷其成因和加以治療,是可以逆轉的。與認知障礙症相似的認知上缺損,有時可能會與譫妄症或抑鬱症混淆。

For older adults who have dementia, feeling confused may be expected. However, when the confusion comes on suddenly or the older person becomes difficult to arouse, this could be a condition called delirium. Delirium causes changes in mental functioning that can closely resemble dementia, but there are two important differences: the speed of onset and level of consciousness. The mental changes in delirium is typified by a rapid change in cognition and is characterized by hallucinations, clouding of consciousness and misinterpretation of events, and sleep disturbance. This type of sudden confusion may be the only sign that the person has another illness and needs medical help right away. It is a reversible illness. Therefore, being able to differentiate between dementia and delirium is crucial for medical professionals.

對於有認知障礙症的年長患者,感到困惑可能是意料中事。然而,當精神混亂是突然冒出來的,或覺醒有困難,這或許是我們所謂「譫妄症」的症狀。<u>譫妄症</u>對大腦機能產生的改

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變,有時會與認知障礙症非常相似,但其中有兩個主要分別,就是發病的速度和知覺意識的水平。典型的譫妄症帶來精神功能的變化是在認知層面上非常急速的改變,伴隨著出現幻覺、意識的模糊、曲解事情、睡眠困擾等。這些突發的混亂症狀,可能是患者出現的唯一徵兆,並需要立即接受醫治。這是可以逆轉的疾病,因此能夠分辨認知障礙症和譫妄症,對醫護人員來說是非常重要的。

## Depression is categorized by the following symptoms:

抑鬱症可以歸納為以下徵狀:

- low or sad mood most of the day 整天心情低落或悲傷
- loss of interest or pleasure 對事物不感興趣,也不愉快
- decreased energy or increased fatigue 體能下降或疲倦感增加
- loss of confidence or self-esteem 失去自信或自尊心
- guilt or lowered self-worth 罪惡感或降低自我價值
- recurrent suicidal thoughts or acts 自殺傾向,包括思想和行動
- poor concentration or slowed thinking 精神不集中或思考遲緩
- agitation or slowing of movement or speech 焦慮不安,動作或講話都變慢
- disturbed sleep 睡眠困擾
- disturbed appetite 食慾不振

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Depression is also a reversible condition and it is important to recognize it early. However, it is difficult as dementia and depression can sometimes coexist, especially in early-stage dementia. Therefore, a referral to psychiatric service should be made for an accurate diagnosis and treatment.

再者,抑鬱症是可以逆轉的狀況,所以及早診治非常重要。然而這是困難的,因為有時認知障礙症和抑鬱症可以同時存在,尤其是在認知障礙症的早期階段。因此應該轉介至精神科服務,以獲取精確的診斷和治療。

An early diagnosis of dementia is important. It helps people receive information, support, and treatment at the earliest possible stage. There is plenty of information about dementia that you or your family may want to know, but first you need a diagnosis.

及早診斷對認知障礙症患者非常重要。這有助患者接收有關資訊、支援服務,和盡早接受治療。坊間有很多關於認知障礙症的資料,可供你或你的家人參考,但前提需要被確診才有作用。

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