

## Understanding the PERSON with dementia (Chapter 2)

The common changes in behaviour.

Caregivers' stories are used to illustrate the difficulties perceived from the person with dementia and the caregivers that require our recognition and response to the hidden meaning of the distressed behaviour.

常見的行為改變。

透過個案故事來闡釋認知障礙症患者與照顧者面對的問題，並需要我們識別煩惱的行為背後含義，和所需作出的回應。

### Common changes in behaviour


As dementia progresses, symptoms come and go. Studies have shown that six areas present the greatest challenge for caregivers. These are aggression, agitation or anxiety, apathy or depression, hallucination and delusions, sleep disturbance, and wandering. Behavioural disturbances of a person with dementia and their management induce stress and burden in family caregivers. This is one of the key reasons for family members to send the person to institutional care. Yet dementia affects the individuals with the condition, who gradually lose their physical and functional abilities. Hence, relatives and other supporters have to cope with seeing a family member or friend becoming ill and decline, while being required to respond to their needs, such as increasing dependency, other than changes in behaviour.

常見的行為改變

當認知障礙症病情發展下去，徵狀會出現，然後又消失。研究顯示，照顧者面對的最大困難，來自以下六個範疇：具攻擊性、焦慮不安、冷漠或抑鬱、幻覺和妄想症狀、睡眠障礙、遊走。要處理認知障礙症人士的困擾行為，會為負責照顧的家人帶來沉重壓力和負擔，這也是家人把患者送到院舍的其中一個主因。與此同時，患者本身的狀況也會受到病況影響，漸漸喪失身體機能。因此，面對上述的行為改變的同時，家屬和其他支援者要應對看著親人或朋友生病和喪失身體機能之餘，還要照顧他們需要，例如變得更依賴。

However, as with most people, those living with dementia do want to remain independent and in control of how and where they live, with the assistance from others. The need of care for people with dementia traverses from community, to residential and hospital settings.

然而，認知障礙症人士和其他大部分人一樣，都希望可以獨立自理，在別人的協助下，也可以控制自己的生活。從社區延伸至安老院舍和醫院，患者均有照顧的需要。

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	Page	1

Recognize and respond to the signs of distress resulting from confusion experienced by the person

The chief cause of behavioural symptoms is the progressive deterioration of brain cells. The exhibited behaviour is more of a reduced ability to adjust to the change of environment and cope with stressors. Behaviours exhibited by the person with dementia, whether one describes it as troublesome, disruptive, or challenging, will require caregivers to consider their purpose or meaning to the persons who display them. All these descriptions of the behaviour reflect the caregiver's view more than the cognitively impaired person's perspective in a situation.

認清並回應因患者感到混亂而導致的窘迫徵狀

行為症狀的主要原因，是腦細胞持續衰退所致。認知障礙症人士表現出來的行為，更多是來自其適應環境改變和壓力源的能力下降。照顧者需要去理解那些被描述為麻煩、破壞、挑戰的行為背後的目的和含義。患者客觀的行為被如何描述和解讀，更大程度上反映了照顧者的想法，而不是從認知受損的患者的角度來考量。

People with dementia are trying to make sense of an increasingly strange world. Stress that they were previously able to cope with would easily develop into distress. Staff or caregivers often find it difficult to respond to distressed behaviour. Yet it is important to take the viewpoint that all behaviour has an underlying meaning. It is our responsibility to find out what the reason is behind the person's behaviour. We therefore must try to put ourselves as much as possible in their shoes and the world of the person with dementia. Trying to control the person will not make the problems go away.

認知障礙症人士面對日益陌生的世界，嘗試去理解很多他們以往可以應付到的壓力，卻逐漸演變成窘迫。院舍職員或照顧者往往難以回應窘迫的行為。然而，重要的是我們知道「所有行為都有其背後的含義」，我們有責任找出患者行為背後的原因。因此，我們必須盡可能站在患者的立場，來看認知障礙的世界；單單嘗試控制患者行為，並不可以解決問題。

The risks of admission to an institution

Admission to an unfamiliar place such as a hospital or residential home can be detrimental to the person with dementia. We need to be aware that medication, environmental influences, and some medical conditions can also cause symptoms, and even worsen or prolong them.

將患者送到院舍的危機

對於患有認知障礙症的人而言，把他們送到如醫院或安老院舍等陌生地方，可能不利於他們。我們需要留意，藥物、環境因素、和醫療狀況等，也可能引起徵狀出現，甚至令原來的徵狀惡化或延長時間。

Patients or residents with dementia often have a number of risk factors. These include high risk of falls, absconding, and aggression. Such behaviour could create considerable misunderstanding, frustration for the extra time required to attend to it, and tension between the person and the care workers. In order to contain these risks, nurses and doctors may instigate control measures, which might include restraining or unnecessarily prescribing sedatives to the person.

患有認知障礙症的人士或院友，通常都會有一些高危因素，包括容易跌倒、潛逃、有攻擊性等。他們的行為會引起誤解、挫敗，需要額外的時間去照顧他們，亦會引起患者與照顧者之間的緊張。為了控制這些風險，護士和醫生可能會採取控制措施，其中包括使用約束物品或不必要地給患者處方鎮靜劑給患者。

Preventing falls was often an important priority for hospitals and residential homes because of the potential injuries caused to the patients or residents. Controlling patient behaviour was a preoccupation for some of the nurses or care workers. Ensuring the “safety” of patients or residents often becomes a prime reason for resorting to restrain measure. The consequential fear of blames from management and liability should not be discounted.

很多時候，防跌在醫院和安老院舍被視為優先的重點，因為這有機會令患者受傷。部分護士或護理工作者視控制病人行為當務之急，為了要確保病人或院友「安全」，成為了決定約束他們行動的主因。這與害怕被管理層責備或責任承擔脫不了關係。

Patients or residents would receive positive attention from nurses and care workers if they were pleasant and undemanding, grateful for the care, and followed instructions, while those who were agitated, aggressive, or disturbing would be labelled as difficult and non-compliant that require an increase in nurses or care workers’ vigilance. As a result, it would make them more unpopular. Nurses or care workers would respond to their struggle with, “Hurry up, I’ve got other things to do”!

如果病人或院友開朗、容易相處、懂得感謝照顧、按規矩，他們會得到護理人員的關注；反之若他們易情緒激動、有攻擊性、令人不安，則會被標籤為麻煩的、不聽話的，需要護理人員加強警惕，結果會令他們更不受歡迎。護士或護理人員或會掙扎：「快點，我還有其他事要忙！」

Allied health therapy was also prioritized for cooperative patients and those with rehabilitation potentials. The care that was not technical, such as bathing and feeding, were considered of minor importance and more likely to be delegated to non-professional staff. Often, people with dementia would not be engaged in activities beyond what were minimally required.

專職醫療人員也會優先提供服務予較合作和有康復潛能的病人。洗澡、餵食等一般被視為不重要的非專業護理，更可能委派予非專業人員來負責。認知障礙症人士往往只能接受最基本的服務。

Restricting personal freedom and choice often leads to distressed behaviour and can result in aggression. The key problem is a reduction in the person’s capacity to do everything. When the emotions and unmet needs that underpin the distressed behaviour are not attended to, we may be tempted to label the person with his/her behaviour, for instance talking about “an aggressive man” and considering many of the associated behaviours to be problematic, difficult to understand, and challenging to deal with.

限制個人自由和選擇，往往導致認知障礙症人士窘迫的行為，並可能引發攻擊性行為。主要問題在於無視一個人做任何事的能力。當情緒和未滿足的需要而引起的窘迫的行為，並未好好處理，我們可能因而試圖以患者的行為來標籤他，例如形容他為「一個具攻擊性的男子」；認為這些相關的行為大都是有問題、難以理解和處理的。

Just imagine a person who used to be managing his/her own hygiene would not be able to negotiate the complexities and confusion of a hospital or a residential home. He/she may start to wet him-/herself and be unable to stay clean. This same person who managed to be happy and live quietly at home, sleeping at night, and entertaining him-/herself by day will be kept awake by the noise and light at night, and bored to death in the daytime.

試想像一個向來可以處理自己個人衛生的，將不能在醫院或院舍的複雜而混亂的環境下適應自理。他們或會開始大小便失禁，不能保持個人清潔。同樣一個人，以往可以在家裡愉快寧靜地生活，晚上好好睡覺，早上自娛，在醫院或院舍中將變成晚上被噪音和光線弄到不能入睡，而早上則被悶死。

Whose problem is it then?


In institutional settings such as hospital and residential homes, there are two factors, namely facility-related and staff approaches, that posed an enormous impact on the occurrence of behavioural symptoms.

究竟是誰的問題？

在院舍環境下，例如醫院和安老院，有兩個因素對引發行為徵狀有重大影響，包括院舍設施和員工的照顧方法。

Facility-related factors create a “context of care” that may contribute to the occurrence of behavioural symptoms. The physical design of the facility, along with the facility routines, policies, and other environmental features, such as the provision of safe outdoor area, use of noxious alarms on doors, or public address systems, have an impact on the social climate. The social environment may either create opportunities, or provide “negative and restrictive feedback” that fosters the development of behavioural symptoms. The level and type of stimulation often serves as an antecedent to behavioural symptoms. These factors are often not being controlled by caregivers, but are determined by facility policies made by the administrative personnel.

設施相關因素產生了一個「照顧的環境」，這個環境可能促使行為徵狀的出現。院舍設施結構上的設計，連同設施的日常常規、政策和其他環境特徵，如安全的戶外空間、門上的警報裝置、公共廣播系統等，都對社交環境有影響。社交環境可以創造機會亦可以提供「負面和約束的反饋」，孕育行為徵狀的發展。行為徵狀的前因通常會成為引發徵狀的刺激程度和行為表現。這些因素往往不由照顧人員控制，而是由管理層所定立的院舍政策決定。

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	Page	4

In addition, formal and “informal” facility policies create work expectations, and influence what the staff feel they can, and cannot do, in adjusting or changing care routines. For example, the person with dementia, Mr. Chan, may be accustomed to getting up at 9 a.m. to take his breakfast. Mr. Chan resists getting up at 7 a.m., and often pushes, and yells at caregivers to “stop”. Staff would consider it difficult to make such allowance to Mr. Chan as this would defer the whole morning routines. Finding a reasonable solution to this “deadlock” will likely require an administrative input or innovative ideas from staff. “Why not tell Mr. Chan the time is 9 a.m. instead of 7 a.m.?”

與此同時，正式和「非正式」的院舍政策產生了員工對工作的期望，影響他們認為甚麼可以或不可以做，調節和改變日常的護理工作。舉例說，有認知障礙症的陳先生，習慣了早上9時起床吃早餐。他不肯在早上7時起來，常與照顧人員推撞和叫嚷「不要吵我」。員工覺得難以容許陳先生晚點才起來，因這會拖遲整個早上的日常工作。要有效突破這個「僵局」，需要員工在執行上的創意思維，例如「可告訴陳先生已經是9點呢？」

Staff approaches to a person with dementia are also critically important to the occurrence of behavioural symptoms, and the outcomes after the behaviour occurs. Communication skills and strategies, including both verbal and nonverbal messages, are very important in dementia care. Changing how requests are made, as well as how caregivers approach and interact with the person, makes a huge difference in the outcome of the care. For example, using strategies to help persons with dementia conduct their own activities of daily living, instead of “doing things to” them because it is “faster” or thinking the person is unable, can reduce reactions related to invasion of personal space and privacy. Developing skills in using validation, distraction, reassurance, and other comfort measures are therefore essential.

員工對認知障礙症患者的態度，對於行為症狀的發生以及行為發生後的後果也至關重要。語言及非語言的溝通技巧和策略，在照顧患者上非常重要。改變的照顧者對患者的應對與互動，會對照顧的結果造成極大差別。譬如說，技巧地協助患者負責自己的日常自理生活，而非單向地幫他們做這些工作，僅因為照顧者覺得可以「快一些」或認為患者沒能力自己做，就可以避免入侵患者的私人空間和私隱，減低衝突機會。因此，利用予以肯定、分散注意、消除疑慮，或其他可以讓患者寬慰的技巧尤其重要。

As mentioned in an earlier section, negative perceptions and labelling of persons with dementia contribute to the development of a cycle of mutual distress. Those feelings, perceptions and labels contribute to a downward spiral in care as in:

如前節所述，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。這些感受、觀念和標籤，令照顧的過程形成以下的惡性循環：

The person with dementia is “difficult”, “hard to manage”, or even “aggressive”

認知障礙症患者「很難相處」、「難以應付」，甚至「有攻擊性」



Caregivers attempt changing the person’s behaviours, not necessarily what the person does

照顧者嘗試改變患者的行為，不理會他做了甚麼



If they are not successful, the person is labelled, “Troublesome”, “Disturbing”,

“Mean”, “Manipulative”, “a Disaster”

如果他們不成功，患者會被標籤為「麻煩」、「煩擾」、「刻薄」、「喜歡擺佈人」、「是災難」



No new interventions are tried because THE PERSON IS the “PROBLEM”

不會嘗試其他干預方法因為「那個人就是問題所在」



Caregivers “cope” by ignoring or avoiding the person

照顧者以漠視或逃避那名患者來「應付」這狀況



The person is not comforted or assisted and behaviours become more intense

患者得不到安慰或協助，而行為更為極端



Caregivers feel *even more distressed and frustrated* by the behaviours

照顧者因而感到更加困擾和氣餒



Caregivers *avoid, ignore, or even “fight back”*

照顧者逃避、漠視，甚至「反擊」



The person’s behaviours continue, and often become even more intense

患者不良行為繼續發展，很多時候變得更为嚴峻



And Round AND Round We Go! Nobody “Wins”!

這樣的循環沒完沒了！沒有人是「贏家」



The person may be extremely scared and perhaps agitated, in particular, when they are admitted to an unfamiliar place as in a hospital. It requires health care providers to acknowledge and respect the feelings of the patient no matter how irrational he/she may appear to us. It is important to understand that the person is not trying to be difficult and the behaviour can be a form of communication. Try to consider and operate on how the patient experiences and feels. This helps promote a person-centred approach to care and to improve their quality of life. A person-centred approach to communication is essential to care of people with dementia.

患者進入了如醫院等陌生環境時，可能會極度恐慌，和焦慮不安。這時候他們需要醫護照顧者去確認這問題和尊重患者的感受，不管那看起來多麼無理荒謬。重要的是，要明白到患者並非固意為難別人，有些行為可能是他想和別人溝通的方法。嘗試在患者的角度考慮他的經歷和感受，有助推廣以人為本的照顧模式，改善生活質素。以人為本的溝通方式對照顧認知障礙症人士非常重要。

It is helpful to understand what causes dementia and the areas of the brain being affected, but the best way to support people with dementia is to get to know about them as individuals. Dementia is more than just “forgetfulness”, as people commonly think. Memory problems are certainly a component of dementia, but communication, emotional, and behavioural problems are often also present. There is no golden rule as to how to handle these behaviours. A key message is that the person with dementia will have worse symptoms if they are facing a lot of challenges.

了解甚麼原因導致症狀產生，和腦部那些部位受到影響固然重要，但支援患者的最好方法，就是當他們是獨立個體那樣去了解他們。認知障礙症並非人們普遍認為的「健忘」。記憶問題絕對是症狀一部分，但患者同時會有溝通、情緒、行為等問題出現。對於這些行為，並沒有所謂金科玉律，重點是，當患者要同時面對很多挑戰時，他的病情會變差。