

Understanding the PERSON with dementia (Chapter 3)

Building a care journey of respect and empowerment.

In this course, we focus on the non-pharmaceutical mode of care to people with dementia by adopting person-centred and intrinsic-capacity approaches.

建立尊嚴與賦權的關愛旅程。

在這節課程，我們將集中討論非藥物治療法，著重以人為本、發揮認知障礙症患者的內在能力等照料模式。

No matter what the cause of the dementia is, difficulties in remembering familiar routes when returning home and problems managing finances and relating other established routines are commonly experienced by the person in the first phase of the condition. As the condition progresses, the person becomes more dependent in daily activities of living and may require assistance with maintaining continence, eating and drinking, and attending to personal hygiene.

不管是甚麼原因導致認知障礙症，不少人在初期時普遍都試過，明明是熟識的回家路想記起時卻有困難，處理財政或日常生活時出現問題等經歷。當病況發展下去，他在日常生活中會變得越來越依賴別人，如避免失禁、照顧飲食、處理個人衛生等。

Biomedical care and technological interventions downplay the traditional nursing component of empathetic caring in which each patient is considered a unique individual worthy of the attention they require. Yet people with dementia whose self-care abilities are declining could attract a label of unworthiness.


專注於生物醫學的治療和運用科技的介入，貶低了傳統護理中以同理心照顧認知障礙症人士的價值，這是對每人都予以感同身受的方式，每個人都是需要別人關注的獨特個體。然而，認知障礙症人士因為自理能力下降，會惹來「無價值」等標籤。

Hospitalization can cause significant distress to people with dementia, where enforced dependency and unfamiliar environments negatively impact the patients' well-being, leading to functional decline and deficits. Person-centred care promotes the strengths of people with dementia and honours their values and choices. It emphasizes shaping the care environment to value personhood, addresses the unmet needs of people with dementia, and prioritizes their needs beyond care tasks. Personhood is a status that is imparted upon one human being. By others, it implies recognition, respect, and trust. Through such recognition, respect, and trust, the personhood of an individual, as well as their well-being, will be enhanced.

住院可能會為認知障礙症人士帶來窘迫，強迫依賴和陌生環境，對其健康和狀態均有負面影響，並引致身體機能的下降和耗損。以人為本的照顧，提昇認知障礙症人士的優點、尊重他們的價值和選擇。以人為本的照顧，強調營造一個尊重人格的環境，解決認知障礙症人士未得到滿足的需要，並將他們的需要置於照顧任務之上，獲優先處理。人格指的是一個人被授予的地位，對其他人來說，這代表了認同、尊重和信任。透過別人的認同、尊重和信任，他的個人生活質素和幸福感也將有所提升。

On the contrary, undesirable interactions in response to the person's behaviour can undermine the personhood, leading to ill-being of the person with dementia.

相反，如我們因為他的行為而產生不良的互動(如惡言相向)，會從根本破壞他的生活質素，令他苦不堪言。

	File	Handout - Understanding the PERSON with dementia (Chapter 3)
	Copyright	© 2020 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	1

Person-centred approach:

以人為本的方法：

In the VIPS framework, Brooker summarizes Kitwood's philosophy of person-centred care for persons with dementia into four major elements with the acronym "VIPS".

布道恩 (Dawn Brooker) 對姬湯姆 (Tom Kitwood) 針對認知障礙症人士的以人為本照顧法的理念，總結為四個主要元素，縮寫為「VIPS」。

The four aspects of person-centred care, according to the VIPS framework, comprises:

根據VIPS框架，以人為本照顧的這四個方面包括：

V stands for a value base that asserts the absolute value of all human lives, regardless of age or cognitive ability, and retains as much independence and dignity as possible

V (Value, 理念) 維護所有人類生命的絕對價值，不論年齡和認知能力，盡力保持獨立和尊嚴。

I stands for individualizing that recognizes and appreciates the variety of characteristics that make individuals unique

I (Individual, 個人核心) 認同與欣賞人們性格多樣化，每個人都是獨一無二的個體。

P stands for understanding the world from the perspective of the person living with dementia


P (Perspective, 前提) 從認知障礙症人士的角度，了解他們的世界。

S is the positive social psychology in which the person living with dementia can experience relative well-being, as equal partners in developing support to make sure it is appropriate for their needs

S (Social, 目標) 正面的從社會心理學出發，讓患者也可以保持相對良好的狀態，作為平等的伙伴，與照顧者共同探討所需的支援服務，務求切合他們自己的需要。

Kitwood argues that the experiences and actions of the person with dementia are affected by more than just the disease process. Neurological and sociopsychological factors, together with a negative interplay between them, combine to deny the person with dementia a sense of personhood. This occurs as a result of care practices such as infantilization, intimidation, stigmatization, and objectification, which create the "malignant social psychology" where the individual is depersonalized, invalidated, and treated as an object.

姬湯姆指出，認知障礙症人士的經驗和行為受到多方面的影響，並不單純來自病情的進展。當神經學和社會心理學因素相互有負面影響時，將會剝奪他的人格感。這些不良的負面影響，來自一些照顧的方法，例如將他當成幼兒看待、威嚇、污名化、物化患者等，導致「惡意的社會心理」出現，令其喪失自我感和被物化。

	File	Handout - Understanding the PERSON with dementia (Chapter 3)
	Copyright	© 2020 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	2

Hence, the goal of a person-centred approach to care is to respect personhood despite cognitive impairment. A key attribute of settings where people with dementia have their personhood recognized is that they experience a sense of attachment, inclusion, identity, occupation, and comfort.

因此，以人為本的照顧方式，則無論他認知能力的障礙如何，都會尊重其人格。若其人格備受認可，他們在那地方可以依附，被接納，有身份，有消遣和舒適。

Care can be operationalized from two perspectives:

照顧可以在兩個層面上執行：

1. Enhanced medical care, which includes moderating intrusive interventions such as catheters, feeding tubes, a physical restraint-free policy, appropriate and modest use of psychotropic medications, careful attention to hydration, bowel and bladder care, and encouraging mobilization.

1. 改善醫療照顧，包括緩和和入侵性治療，如導尿管、餵飼管，避免身體約束的政策，適度使用精神類藥物，脫水及排泄護理，鼓勵多走動。

2. Enhanced psychosocial care, which includes prioritizing patient needs over tasks, encouraging family members and volunteers to provide companionship, and engaging in daily structured activities such as music therapy, and recreational or group activities.

2. 增強的社交心理護理，包括將患者需要優先於工作任務之上，鼓勵家人和義工多陪伴患者，並參與日常結構性的活動，例如音樂治療、娛樂或小組活動。

It is necessary to enhance the social environment that encourages the presence of families, volunteers, and domestic helpers who can serve as important partners in the health care team. They can help in daily activities such as engaging the person with dementia in activities and conversations. Family caregivers' participation is imminent in patient care. The presence opportunities serve to equip caregivers with enhanced skills and confidence to care for the patients after their discharge, and more importantly, be the familiar faces to the person with dementia.

我們需要改善社交環境，鼓勵家人、義工、家傭參與，作為護理團隊的重要合作伙伴。他們可以在日常活動中，幫忙勉勵認知障礙症人士參與活動和展開對話。家庭照顧者的參與，在其照顧過程中有迫切的需要。透過出現在這些活動中，照顧者可以改進技巧，提升信心去照顧出院後的患者，以及最重要的是讓認知障礙症人士感到有熟識的面孔。

As the person-centred care places primacy of the relationship with the individual over the completion of tasks, organizations need to empower professionals to adopt this approach to care delivery.

以人為本的照顧服務，把個人關係放在首位，高於完成任務，因此院舍機構需要賦予專業人士權力，以這樣的方式提供照顧服務。

The basic tips for avoiding disturbed behaviour

Communication difficulties can be one of the most upsetting aspects of caring for someone with dementia. It is frustrating both for the person and for family members. Although it can be difficult to understand why people with dementia act the way they do, the explanation is attributable to their disease and the changes it causes in the brain. It is absolutely crucial that we do not label a person as “difficult” or “uncooperative”. If we use negative language to assume the underlying causes of their behaviour, we are failing to try and understand their behaviour. The behaviour will continue and will be harder for us to respond to. Familiarize yourself with some of the common situations that arise when someone has dementia, so that if you encounter the person with dementia saying something shocking, you will know how to respond calmly and effectively.

避免問題行為的一些基本建議

照顧認知障礙症人士，溝通困難可以是最苦惱的問題之一，困擾著他本人和其家人。雖然我們或者難以理解為什麼他們會有這樣的行為，但那是因為疾病令到其腦部有所改變而造成。絕對的關鍵是不要把他們標籤為「難相處」或「不合作」，因為如果我們用負面的用詞來妄斷他們問題行為的原因，我們則不能嘗試去理解他們的行為。這樣的話，問題行為將會繼續下去，令我們越來越難以應對。多讓自己熟識一些患有認知障礙症的人普遍的情況，將有助你在遇到認知障礙症人士的困惑徵狀時，知道如何冷靜和有效地回應。

The expressive or receptive exchange of information is vital to the functional success and emotional well-being of a person with dementia.

從善如流的溝通交流，對認知障礙症人士的功能和情緒健康極其重要。

Communicate sensitively to support meaningful interaction

A person-centred approach that is grounded in dignity and respect is a key to communicating effectively with a person suffering from dementia.

體貼的溝通以支持有意義的互動

建基於尊嚴和尊重的「以人為本模式」，是與認知障礙症人士有效溝通的關鍵。

The 10 communication tips:

十項溝通建議：

TIP 1: Gain attention and trust

The person feels safe with you and that you have his/her agreement and approval to proceed.

E.g., “Good morning, Ms. Chan. It’s time for breakfast.”

建議 1：贏取注意和信任

讓他/她覺得安全，和你需要有他/她的同意和批准才繼續。

例子：「早晨，陳女士，現在是早餐時間了。」

TIP 2: Approach from the front

Talk with the person at eye level helps show that you are listening and gives him/her an opportunity to recognize you.

建議 2：面對面與人交談

在視線的高度與他/她對話，會讓他/她覺得你會聆聽，也是給他/她認識你的機會

TIP 3: Minimize distractions

Try to eliminate all unnecessary sources of stimulation. E.g., “Mr. Chan, let’s turn the volume down on your radio.”

建議 3：將外來騷擾減到最低

嘗試清除所有不必要的刺激源頭。例如：「陳先生，不如我們把收音機的音量收細。」

TIP 4: Lead with the person’s name

Calling a person with dementia by their name shows respect, and identifying yourself often helps the person with orientation. Do not talk down to the person or speak to him/her as if he/she were a child. E.g., “Good morning, Mr. Chan, I am So-and-So. How are you feeling today?”

建議 4：以名字稱呼對方

以名字稱呼認知障礙症人士會顯得尊重，而自我介紹則往往可以幫助他們適應。不要像對小孩子那樣的語氣跟他們對話。

例如：「陳先生，早安，我是素素，你今天感覺怎樣？」

TIP 5: Avoid pronouns

Use simple sentences, and avoid words like *it, he, his, she, her, them, they, and those*, as far as possible. These will often frustrate and confuse. E.g., “Mr. Chan, when did May May leave?” (not “... when did ‘she’ leave?”)

建議 5：避免代名詞

用簡單句子，盡量避免使用它、他、她、他們、那些等字，因為這些往往會令他們混淆和氣餒。例如：「陳先生，美美是甚麼時候走的？」（並非「...她是甚麼時候走的？」）

TIP 6: Use short sentences


Keep sentence simple and direct. Overloading with lots of information can be confusing. For example, if you ask, “Would you like chicken for dinner?” This only requires simple yes or no, or a nod or shake of the head. In contrast, if you asked, “What would you like for dinner?” It requires remembering, finding, and saying the right word. That will be a process extremely difficult to the person.

Also, do not ask questions he/she cannot answer, such as “What is my name?” or “Do you remember your grandchild’s name?” This will only lead to unnecessary frustration and stress.

建議 6：使用短句

保持句子簡單直接，加上過多資訊會讓人混亂。例如你問「你今天晚餐想吃雞嗎？」這只需要簡單回答是或否，或點頭或搖頭。相反，如你問：「你今晚想吃甚麼？」這需要在記憶尋找對的字來回答，可能是極度困難的。

還有，不要問一些他們回答不了的問題，如「我叫甚麼名？」或「你記得孫兒的名字嗎？」這只會徒添不必要的煩惱和壓力。

	File	Handout - Understanding the PERSON with dementia (Chapter 3)
	Copyright	© 2020 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	5

TIP 7: Wait for a response

The response can be delayed by up to 30 seconds. This delay might allow him/her time to process your words. Be patient.

建議 7：等候回應

回答的延遲可能會長至 30 秒，延遲回應讓他們有時間去消化處理你的問題。請耐心點。

TIP 8: Use visual or tactile cues to illustrate your words

For example, while saying “Pick up the chopsticks to eat”, demonstrate the holding of the chopsticks and the bowl. While saying “It’s time to eat”, put your hand to your mouth to simulate eating.

建議 8：說話以外用視覺的或觸覺的提示加強表達

例如：說「拿起筷子吃東西」時，同時展示拿起碗筷。當說到「是時候吃東西了」，將手放到口邊模仿吃東西的動作。

TIP 9: Watch your nonverbal messages

Nonverbal messages can be both intentional and unintentional. Be careful not to change the meaning of your message with your nonverbal cues. E.g., Avoid crossing your arms, as this indicates impatience. Remember to keep a smile.

建議 9：留意你的肢體語言

非口頭的訊息可以是故意或無心的，所以要小心別讓你的肢體表達改變了你說話的原意。例如：避免蹺起雙手，因為這動作顯得你不耐煩。記得保持微笑。

TIP 10: Be patient, supportive, and friendly

At every stage of dementia, there is a person behind the patient.

建議 10：保持耐性、鼓勵和友善

在認知障礙症的每個階段，都需要有一個人來支持患者

Whenever possible and appropriate, use additional forms of communication to express support, such as touches, when appropriate, and smiles. Focus on the feelings related to their communication, not just the facts.

盡可能在適當時候使用額外的溝通模式以表示支持，譬如合適情況下拍拍對方一下、笑一下。專注於他們在溝通時的感受，而不只是表面的形式事實。

Promote independence and encourage activity

Instead of asking, “What’s the matter?”, how about asking, “What matters to YOU?”

提倡獨立和鼓勵活動

與其問「發生甚麼事？」，不如問：「你覺得甚麼事對你是重要的？」

According to the World Health Organization, our focus now turns to the attention to intrinsic capacities of a person instead of merely identifying and treating acute episodes of illness. *The WHO programme identifies 5 intrinsic capacities: Mobility, Cognition, Vitality, Psycho-social, and Neuro-sensorial with vision and hearing.* The inability of a person to undertake various activities of daily living without the assistance of others happens as a result of a significant loss of intrinsic capacities. A return to the intrinsic capacities has the potential to design interventions for improving the health of an individual. It emphasizes the optimization of a person's intrinsic capacities to their fullest, in order to manage his/her life and well-being as independently as possible. So we should focus on the person's abilities and what he/she can still do. Caregivers are doing "with" instead of "for" the person. Maximize freedom and minimize control whenever possible.

根據世界衛生組織，我們現在應該將注意力集中於人本質的內在能力，而不只是確認和治療嚴重的疾病。世衛指出五項內在能力：行動能力、認知能力、生命力、社交心理、感覺神經：視覺和聽覺。若這些內在能力大量喪失，將令人不能自理日常生活，而需要靠別人協助。要確保認知障礙症人士在逐漸失去身體功能的晚期，仍然可以有尊嚴地生活，我們提倡要加強內在能力的行為訓練，發揮個人獨立自理的最大潛力。因此，我們要專注於患者仍然可以做到些甚麼，照顧者是「和」他一起做，而非「幫」他做，盡可能給予他最大自由度，而把控制減到最少。

Employing the person-centred principles brings us back to basics and explores what it means to be a person: the "small things" that may have meant a great deal to a person. These include staff taking time to say hello, and giving information and reassurance. Recognize the importance of intrinsic capacities for the person's condition of dementia rather than labelling it as a disease. The goal is to allow the persons to keep their dignity and autonomy as much as possible while providing them with the help they need.

以人為本的原則，帶我們回歸基本步，探討人之所以為人的意義。看似微不足道的「小事」對認知障礙症人士來說可能意義重大，包括員工花少少時間說句「你好」，給予資訊和安慰。對認知障礙症人士人發揮內在能力的重要性予以確認，而不是簡單地標籤那是一種疾病。這一切的目標，是在讓他們維持尊嚴和獨立自主的同時，提供他們所需的幫助。