

How to Support Employees with Dementia at Work – A Practical Guide for Employers



平等機會委員會
EQUAL OPPORTUNITIES COMMISSION

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1. Introduction

Every three seconds, someone around the globe develops dementia. In 2020, there were over 55 million people living with dementia worldwide. It is generally believed that dementia only affects older people, but in fact, younger people can also experience dementia. The World Health Organisation reported that up to 9% of those with dementia experience young-onset dementia (YOD), defined as the onset of symptoms before the age of 65. These people are often still working when diagnosed with dementia.

Furthermore, as more and more older people remain in the workforce, the number of working people with dementia is expected to rise. Despite this growing trend, the specific needs and rights of this working population living with dementia have not been fully understood or addressed. Employers will need to be ready to tackle the challenges of supporting employees with dementia.

2. Dementia in Hong Kong

In Hong Kong, research estimated that around 100,000 people were living with dementia in 2009, and this is projected to soar to over 330,000 people in 2039. Additionally, there are over 13,000 people who have YOD, with the youngest onset age found being 38. The prevalence of dementia is likely underestimated, as many cases go undetected due to people not seeking help in the early stages of symptoms and the prolonged process of obtaining a formal diagnosis.

Meanwhile, working carers for people with dementia may experience high levels of stress and emotional demands. Balancing caring responsibilities with work duties can be extremely challenging, forcing some carers to leave the workforce.

The purpose of this toolkit is to promote a better understanding of dementia and the working population with dementia, and offer guidance

for employers on supporting employees with dementia and those caring for people with dementia.

3. Rights of People with Dementia and Carers

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes the rights of persons with disabilities (PWDs) to fully participate in society on an equal basis with others. In particular, Article 27 of the CRPD stipulates the right of PWDs to work, including the right to the opportunity to earn a living by work freely chosen or accepted in a work environment that is open, inclusive and accessible to PWDs. The realization of the right to work for PWDs, including those who acquire a disability during employment, should be achieved by appropriate steps.

In Hong Kong, the Disability Discrimination Ordinance (DDO) protects the rights of PWDs. Under the DDO, the definition of disability includes “malfunction, malformation or disfigurement of a part of the person’s body” or “a disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgement or that results in disturbed behaviour”. According to the Hong Kong Alzheimer’s Disease Association, dementia refers to degenerative brain syndromes that affect one’s memory, language, thinking, behavior, emotions and sensory system impairments. The person may lose control over his/her impulse system, and in the final stage, may have complete memory loss.

Accordingly, dementia is a form of disability covered by the DDO. The DDO prohibits both direct and indirect discrimination against PWDs based on his/her disability in various public domains, including employment.

As stated in Sections 6 and 11 of the DDO, direct and indirect discrimination are defined as follows:

- Direct discrimination occurs when, on the ground of disability, a PWD is treated less favourably than someone without a disability in similar circumstances.

- For instance, there may be direct discrimination if an employer does not provide training opportunities to an employee because of his/her dementia.
- Indirect discrimination involves imposing a seemingly neutral condition or requirement on everyone, but such condition or requirement has a disproportionate adverse effect on a PWD and the application of such condition or requirement is not justified in the relevant circumstances.
- For example, there may be indirect discrimination if an employer cannot justify why a full attendance requirement is needed before an employee is eligible for receipt of a bonus payment when an employee with dementia is unable to meet the requirement because he/she needs to be away from time to time to receive medical treatment.

Concerning the rights of carers, the Family Status Discrimination Ordinance (FSDO) states that it is unlawful to discriminate against someone on the ground of his/her family status. “Family status” is defined in the Ordinance to mean the status of having a responsibility for the care of an immediate family member (i.e. a person who is related to someone by blood, marriage, adoption, or affinity). The FSDO provides protection for carers in various public domains, including employment.

4. Understanding Dementia

Dementia is an umbrella term referring to various degenerative brain syndromes affecting one's memory, thinking, behavior and emotions, etc. There are numerous types of dementia arising from different causes, with Alzheimer's disease being the most common type (50% - 70% of dementia cases). The impact of dementia can be broadly categorised into early, middle, and late stages.

Types of dementia

- Alzheimer's disease, Vascular dementia, Frontotemporal dementia, Dementia with Lewy bodies and others

Table 1. Common difficulties faced by people with dementia

Memory	Experience difficulties in remembering recent events and may repeatedly ask the same question
Thinking	Struggle with concentration, grasping new ideas, and problem-solving
Communication	Encounter challenges in finding the right words, following conversations, reasoning, and interpretation
Time or place	Become disoriented and lose track of time, date, and place
Sight and visual perception	Experience difficulties in judging distances
Mood	Exhibit unusual sadness, fear, or anger and may lose interest in previously enjoyed activities

It is crucial to note that dementia affects people in different ways, depending on the condition and the person. Particularly, the causes,

characteristics, and challenges of young-onset dementia (YOD) differ from those in older people with dementia. These differences can be summarised as follows:

Table 2. Causes and characteristics of young-onset dementia

Causes	<ul style="list-style-type: none">• The causes of YOD are more extensive than those of general dementia.• For example, alcohol consumption, metabolic effects, genetic diseases, depression, and vitamin deficiency etc.
Characteristics	<ul style="list-style-type: none">• Memory loss might not be the initial sign.• Early stages can present with changes in behaviour, language, vision, and personality, which may be confused with other mental health conditions.• There is also an increased likelihood of experiencing challenges with movement, walking, physical coordination, and balance.• Difficulty getting a diagnosis because early symptoms are hard to recognise.

5. Myths about Dementia

Myth 1: Being forgetful is just normal as we get older.

Reality: Some forgetfulness is normal as we age, but people with dementia may have memory issues that affect daily functioning, particularly in short-term and working memory¹. They may forget recently learned information, the name of a close lifelong friend, the route to navigate to a home they have lived in for decades, or ask the same questions repeatedly because they forget they have already asked them.

Myth 2: It is best for employees with dementia to stop working after diagnosis.

Reality: After diagnosis, while continued employment may not be an option for all employees with dementia, studies have found that remaining employed can enhance the well-being of those living with the condition. Employees who continued working reported that the routine of working kept them socially connected and provided them with structure and purpose, compared to those who left their jobs after diagnosis. Meanwhile, the employees' accumulated strengths and skills are beneficial to the company.

*“The more I do, the longer I’ll keep some sort of good function there.”
– A 58-years-old woman living with Alzheimer’s disease.*

Myth 3: Dementia is just being unable to do anything.

Reality: People with dementia can still accomplish many tasks with guidance. Those in the early stages of dementia experience mild impairment but can take care of themselves, make decisions, and maintain significant work capabilities. Dementia manifests differently in each person, allowing some to sustain employment for a period if their symptoms permit. It is crucial to understand that dementia does not instantly render someone unable to work, particularly in the initial stages. The emphasis should be on recognising their existing strengths and abilities.

¹ Working memory is the system or systems believed to be essential for retaining information in mind while performing complex activities like reasoning.

Myth 4: There is no cure for dementia.

Reality: While there is currently no cure for dementia, there are medications that can help manage dementia symptoms. Non-pharmacological interventions are also available to support people living with the condition and their carers. People with dementia can maintain their quality of life by participating in physical activities, cognitive stimulation exercises, as well as social interactions.

Myth 5: Parkinson's disease is dementia.

Reality: Parkinson's disease and dementia are two different conditions. Parkinson's disease primarily affects a person's movement. However, as the condition progresses, some people living with Parkinson's disease may experience cognitive difficulties, including issues with thinking and memory, and may eventually develop dementia.

6. Becoming a Dementia-Friendly Workplace

Employment provides employees living with dementia with more than just a paycheck; it gives them a sense of purpose and fulfillment, which helps preserve their self-esteem and social connections. Established principles² for creating dementia enabling environments already exist in settings such as homes and public buildings, which promote independence and support well-being of people with dementia. These principles are also applicable for creating a dementia-friendly workplace. By doing so, companies can demonstrate empathy, support team members through cognitive stimulation via work, and implement a smart business strategy.

6.1 Communication with Employees Living with Dementia

When an employer or manager observes signs of dementia in an employee³, or if an employee discloses a dementia diagnosis or is undergoing evaluation, it is crucial to maintain open communication. Although dementia may affect a person's ability to communicate, there are strategies that employers or managers can use to enhance communication with employees who have dementia. The main focus should be on establishing a calm and attentive atmosphere that caters to the employee's cognitive and communication skills, while also being adaptable and supportive.

² Please refer to item 10 of part 5 of the Reference materials.

³ For ease of reading, the term "employee" mentioned in sections 6.1 and 6.2 refers to "employee with dementia".

Table 3. Dos and Don'ts when communicating with employees living with dementia

Dos	Don'ts
Find a suitable place to speak with minimal background noise and distractions.	Interrupt or finish the employee's sentences.
Maintain eye contact to help the employee stay focused.	Speak with a tense tone or speak loudly.
Keep sentences short and simple.	Ask too many questions at once.
Utilise visual aids such as paper or a whiteboard if available, and provide a written or audio record after a discussion.	Assume what the employee can or cannot understand.
Observe the employee's behaviour and body language that may indicate their feelings. Offer reassurance when needed.	Ask questions rapidly and repeatedly about whether the employee remember something or someone.
Be patient. Give the employee time to process information and respond.	Question the employee's memory problem when frustration occurs during communication, as that may be common.
Check the employee's understanding after verbal explanation.	Talk down or turn away as if the employee is not there.
If the conversation becomes frustrating, consider taking a break and talking later.	Call the employee demented.

6.2 Providing Reasonable Work Accommodation

Dementia is a progressive condition. With appropriate work accommodation, employees with dementia can continue to work. Work accommodation refers to any modifications or adjustments made to a job, employment practice, or work environment that enable persons with disabilities to have equal employment opportunities.

❖ **Key points to consider when deciding on work accommodation**

- What limitations are the employees facing?
- What specific job tasks are problematic due to these limitations?
- How do these limitations affect the employees and their job performance?
- What are the strengths and skills that the employees have developed over time?
- Is there any available accommodation to reduce or eliminate the problems?
- Has medical advice been sought, such as from a doctor or occupational therapist?
- How effective will the adjustment be in supporting the employees' limitations?
- How practical is it to implement the adjustment, considering the time and any additional training required?
- What are the financial costs, and are they considered reasonable given the employer's resources?
- What disruption, if any, will be caused by making the adjustment?

The work support provided to employees with dementia should be based on their unique circumstances and professional advice or assessments. To address their specific difficulties, reasonable accommodation may be considered in different aspects of the workplace.

❖ **Working environment**

- Minimise distractions for the employee with dementia by considering installing soundproof structures, providing headphones, or allowing him/her to work in a meeting room if possible. Excessive noise can exacerbate the challenges faced by people with dementia, leading to confusion and behavioural issues.
- Create a space where the employee can take time out if he/she are feeling anxious or overwhelmed.
- Provide clear and bold signage with good colour contrast to help navigate the workplace effectively.
- Adopt a labelling and colour-coding system to assist in organising work.
- Incorporate written or verbal reminders into the employee's daily tasks.
- Post written or pictorial instructions for frequently used machines and routine procedures to enhance understanding.
- Provide a voice-activated recorder to record verbal instructions.
- Encourage the use of dementia-friendly language and foster an appropriate attitude.

Point to note:

Some adjustments to the workplace are actually not expensive at all; it may simply involve rearranging the existing work equipment without any additional expenses.

❖ **Job duties arrangements**

- Break down large tasks into multiple smaller steps.
- Allocate tasks one at a time rather than all at once.
- Use a task list with numbers or symbols.
- Provide guidance on simplifying routines.
- Allow time off from the office for medical appointments or other treatments.
- Offer regular rest breaks during the workday.

- Reduce work hours if medically supported, for example, before or after taking medication.
- Adjust job responsibilities to better align with the employee's abilities.
- Retain familiar job tasks for the employee whenever possible.

❖ **Supervisory support**

- Assign a supervisor to check in with the affected employee to address any employment-related questions.
- Set up a buddy system to assist the employee during times of uncertainty.
- Offer to repeat or write down instructions for the employee as needed.
- Provide more educational talks and training sessions for staff to increase understanding of dementia and reduce stigma.

Mr. Tanno, who is 49 years old, started his career as a car salesman. He received a diagnosis of young-onset Alzheimer's disease when he was 38. Thankfully, his employer was supportive and accommodating. As a result, he was moved from sales to a back-office position. He is currently still working for the same company. (News source: HKET)

At some point, employees with dementia may choose to leave their jobs, or the employer may no longer be able to accommodate them. In these cases, an open discussion about their exit may be inevitable, following the organisation's established policies and procedures.

Maintaining a sense of purpose and engagement is crucial for preserving self-esteem and dignity after leaving the workforce. Employers could consider offering less intense work opportunities for employees with dementia, as returning to a familiar work environment can be pleasant and advantageous for their well-being. Other possible alternatives may include a variety of voluntary activities or a retirement club.

6.3 Providing Support for Working Carers for People with Dementia

As the number of working carers for people with dementia increases, it is crucial to create supportive and open workplace environments that recognise and address their needs. Caring for people with dementia can be particularly challenging due to the unpredictable and sudden nature of these responsibilities, such as managing situations where people may get lost or when carers experience disrupted sleep on most nights. Employers can demonstrate their support for employees who are caring for someone with dementia by implementing the following measures:

- If practicable, provide remote and flexible working policies to help them balance sudden and unpredictable caring duties from home.
- Offer family leave or unpaid leave to ensure that they can take the necessary time off to accompany dependents to regular medical appointments and treatments.
- Encourage working carers to form an informal exchange platform for sharing tips and resources.
- Engage with working carers to understand their specific caring duties and needs.
- Provide resources for working carers to assist in stress management and resilience building, such as Employee Assistance Programs and other awareness talks.
- Implement carer policies consistently throughout the organisation.

7. Sharing from Employees with Dementia and their Carers

The EOC interviewed three people living with dementia and their carers in July 2024. They are Connie, Emma and Ruby (Connie's carer) (Pseudonym).

Connie is 52 years old and was diagnosed with Alzheimer's disease two years ago. At that time, she was working in a healthcare institution and her job duties were procuring drugs and answering phone calls. She left her job about a year after the diagnosis. Before that when she was still working, she experienced disorganised thinking, reduced balance and falls. Her memory became worse and started to lose learning ability. For example, she took more time than before to learn how to order drugs by facsimile and email.

Connie was not aware of the possible link between the above conditions and dementia. She sought medical advice afterwards and was referred to the department of occupational therapy for a cognitive assessment test. It was then that she was diagnosed with the condition. Connie felt anxious after she got the condition and thought that her colleagues were unable to share her feelings.

Connie: "How come I catch such a condition? What should I do?...I was mad at myself when I wanted to say or do something....They couldn't get what I've said and didn't get what I meant....Sometimes I feel like a fool."

Rising to the challenges at work

Connie did not leave her job immediately after she was diagnosed with the condition. She started to use different methods to perform her duties. For example, she would write down the work instructions or audio-record them on her mobile phone, and even use electronic memos to remind herself of outstanding work.

Ruby, Connie's younger sister, said that Connie remained motivated at work.

She said, “Connie is smart. She took photos of the drugs she’d ordered before going on leave. She took photos of what she’d done. During her leave, she would know what’s going on (if her colleagues) called her about any shortfall in delivery.”

If I could go back in time, I wish my employer could

Connie’s employer did not do anything special after they knew that Connie was diagnosed with dementia. Connie did not take the initiative to inform her employer of her needs or ask for assistance either. Looking back, both Connie and Ruby agreed that they should have communicated more proactively with the employer to discuss feasible work adjustment plans.

Ruby: “Looking back...Is there anything they can do to help her in her work....We didn’t know that we can ask (the employer) for assistance.”

Connie: “It would be much better if I was asked to (order one drug) at one time...and if written instructions were given....It would be easier for me if they could take more time to show me the steps....”

Connie wished that she could have a quieter working environment free from noise nuisance to enable her to concentrate more on her work. What she wanted most was for her employer and colleagues to know more about dementia, understand her condition and offer help if needed.

Connie: “(If someone could offer me some help at work,) I would feel happier....That is, there’s someone who understands you. It would be very stressful for me if I work with someone who doesn’t understand my situation, and speaks and works very fast....very stressful.... (If I ask colleagues for help) I may have put pressure on them....It depends on if it is of their business....perhaps they don’t know how to handle some jobs....They will get annoyed (if I ask them).”

Although she has left her job, she still wants to pursue her career because “she feels happy if she can manage (her work).” She said, “I feel so stressful if I go to work, but it’s a waste of time if I don’t.” She wishes to

have a more friendly working environment and assistance from her colleagues in order to boost her confidence.

Explainer

❖ Should employees disclose their disability to employers?

- Disclosure of a disability and requesting accommodation is a personal decision.
- Some employees with disabilities may choose not to disclose their disability if they believe it does not impact their work.
- Stigma and fear of negative consequences may prevent many from disclosing their medical conditions.

❖ Are employers responsible for providing work accommodation?

- Employers should provide reasonable accommodation when they are aware of an employee's disability that affects his/her ability to perform core job duties.
- As stated in section 12 of the Disability Discrimination Ordinance, if a PWD is unable to carry out the inherent requirements of a particular job, it may not be unlawful to discriminate against the PWD. That said, in general, before concluding that a PWD would be unable to carry out the inherent requirements of a particular job, the employer should consider providing reasonable accommodation unless the accommodation would cause unjustifiable hardship.

Points to note:

- *Employers are encouraged to consult with employees with disabilities and seek professional advice for effective accommodation.*
- *Employees with disabilities are encouraged to communicate their needs to employers when necessary.*

Ruby, Connie's younger sister, had a positive approach after she learned about Connie's condition. She however started to be worried after Connie lost her job. She was often consumed by concern for her sister, even at work.

Ruby: "(In the beginning) I didn't have any strong feelings until she lost her job. I started to feel sad....She was jobless suddenly, which has affected our means to a certain extent. I had to figure out at once what she can do in the daytime or how we could help her, instead of letting her simply stay at homeWhat's most difficult is that I can't go home to take care of her because sometimes I return late at night (due to shift work), once or twice a week....When no one could take care of her, I felt very worried....All I can do is to call her during breaks."

Ruby very often has to take leave to accompany Connie for medical consultation or activities. She occasionally faced difficulties and grumbles from her colleagues.

"(When I am on leave) My colleagues will have some grumbles because they don't like (to cover for) my duties...and they don't know much about computers....That's why they don't like it when I take too many leaves. Sometimes they say something like it's better if you're here."

Besides making it easier for her to take leave, Ruby would also like to discuss with her employer the possibility of flexible work arrangement so that she can spend more time with Connie. She also believes that family leave can be of great help to her as it will allow her more time to accompany Connie to see the doctor, especially when Connie will only see the doctor more often.

"Flexible work arrangement works better for me. If my sister's condition gets worse, (I'd like to see whether) I can go to work at a later time. I can go to work after taking her to centre....My employer is willing to communicate but I don't know if it's ok....(If there is family leave) Of

course it fits me perfectly because she (Connie) needs to see the doctor frequently.”

Emma, 66 years old, was diagnosed with mild cognitive impairment⁴ two years ago. She has over 20 years’ experience of working in the insurance industry and is mainly responsible for following up customers’ insurance policies. Recently, there were instances where she forgot to follow up customers’ insurance policies. For example, she forgot to hand in a customer’s cheque for the payment of renewal premium and even missed the deadline for renewing her customer’s policy. As a result, the customer had to take out another policy of a higher value. In the beginning, Emma did not realise that her condition was related to dementia until her younger sister alerted her to her deteriorating memory when she decided to seek medical advice.

Emma: “I didn’t think it (mild cognitive impairment) was a big deal...not a big deal. But my condition started to get worse this year. My memory deteriorated seriously....Sometimes I can remember, sometimes not.”

“Don’t want to cause others any trouble”

Emma did not tell her employer about her condition because she thinks that her employer is unable to help her and she does not want to cause others any trouble. She also thinks that her employer and colleagues lack knowledge of dementia.

Emma: “It’s not necessary to tell anyone because they can’t help me....It is beyond their capability if I tell them my memory is getting worse....(Even if my employer can offer me some support) I don’t want to cause others any trouble.” After she was diagnosed with the condition, Emma used the calendar feature of mobile phones to remind her of her work, but sometimes she still missed some tasks.

⁴ Mild cognitive impairment is not a normal part of ageing. It is a brain condition that involves subtle changes in memory and thinking, but it is not as severe as “dementia”.

About the future...

Considering the potential impact of her condition on customers, Emma started her retirement plan, but she still wants to pursue her career. She would be happy to join any corporate volunteer activities in the future, if any.

Emma: “If there are job opportunities in the future, I will consider returning to the labour market...depending on the nature of the job....It’s ok if I don’t need to often use my memory....I’d like to give it a try....I’d be happy to work if there’s a chance....The job nature has to be more straightforward...without much change....I can hardly follow if things often change after I get used to the pattern. It would be helpful for me if there’s a regular pattern.”

Importance of support from her younger sister

Emma said her younger sister’s support is very essential. After the confirmation of her condition, her sister proactively identified suitable community resources for her, such as Chinese opera singing, fitness classes for the elderly and memory training classes. She hopes to obtain relevant community resources more easily in the future, such as fitness classes and memory training activities, so that she can maintain her health and vitality.

Emma: “My sister asked me to sign up whenever she found something suitable for me....I would be in trouble...without the help of my sister because it is usually my sister who helps me, for example, looking for information of venues or activities....”

Emma is worried about her health and does not want to become the burden of anyone. She also intends to sign the Enduring Power of Attorney (持久授權書).

Emma: “I want to sign the document mainly because I fear that my health will deteriorate....In fact I’m worried that my condition is getting worse....Someone needs to take care of me....That’s not what I want....I

plan to sign the Enduring Power of Attorney so that my younger sister can follow up everything for me.”

Explainer:

Before being diagnosed, people with dementia may think that certain symptoms, such as memory decline, are just a normal part of ageing. This is, however, not the case. The table below outlines the differences between normal ageing and dementia:

Table 4. Differences between normal ageing and dementia

	Possible changes due to normal ageing	Possible changes due to dementia
Memory	Occasionally forget something you were told a while ago.	Forget something that was just recently mentioned or explained.
	Misplace things from time to time.	Put things in unusual places but forget the reasons behind it.
	The key difference is that people with dementia have more frequent and severe memory problems. They may not recall memories even when given hints.	
Language	Occasionally have difficulty finding the right word, but remembering it eventually.	Frequently struggling to find the right word and having problems with understanding and organisation.
Orientation	Get confused about the day or the week, but figuring it out later.	Lose track of the date, season or the passage of time.
	Occasionally forget the destination.	Become lost in familiar places.
Planning and decision making	Find it more challenging to juggle multiple tasks simultaneously, but can manage if given more time.	Have difficulty maintaining concentration on a single task but are able to handle it step by step (with/without guidance).
Mood	Sometimes feel reluctant to join in at work, family or social gatherings.	Become withdrawn and lose interest in work, friends or hobbies.

To detect dementia early, we can test ourselves by self-assessment or seeking professional help. Here are three self-assessment tools provided by different organisations:

- Informant Questionnaire on Cognitive Decline in the Elderly (IQ-CODE) by Jockey Club Centre for Positive Ageing (for family members of people suspected of dementia)



- Dementia Self-assessment tool (AD-8) by Therese Pei Fong Chow Research Centre for Prevention of Dementia



- Electronic Cognitive Screening (EC-Screen) apps by the Chinese University of Hong Kong and Jockey Club Centre for Positive Ageing



Reference materials

Please scan the QR code below for reference materials.



Disclaimer

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The flowers presented on the cover are forget-me-nots, symbolising the memory loss associated with dementia while also conveying hope and reminding society not to forget the needs of people with dementia. This concept originates from Dementia Friends UK.