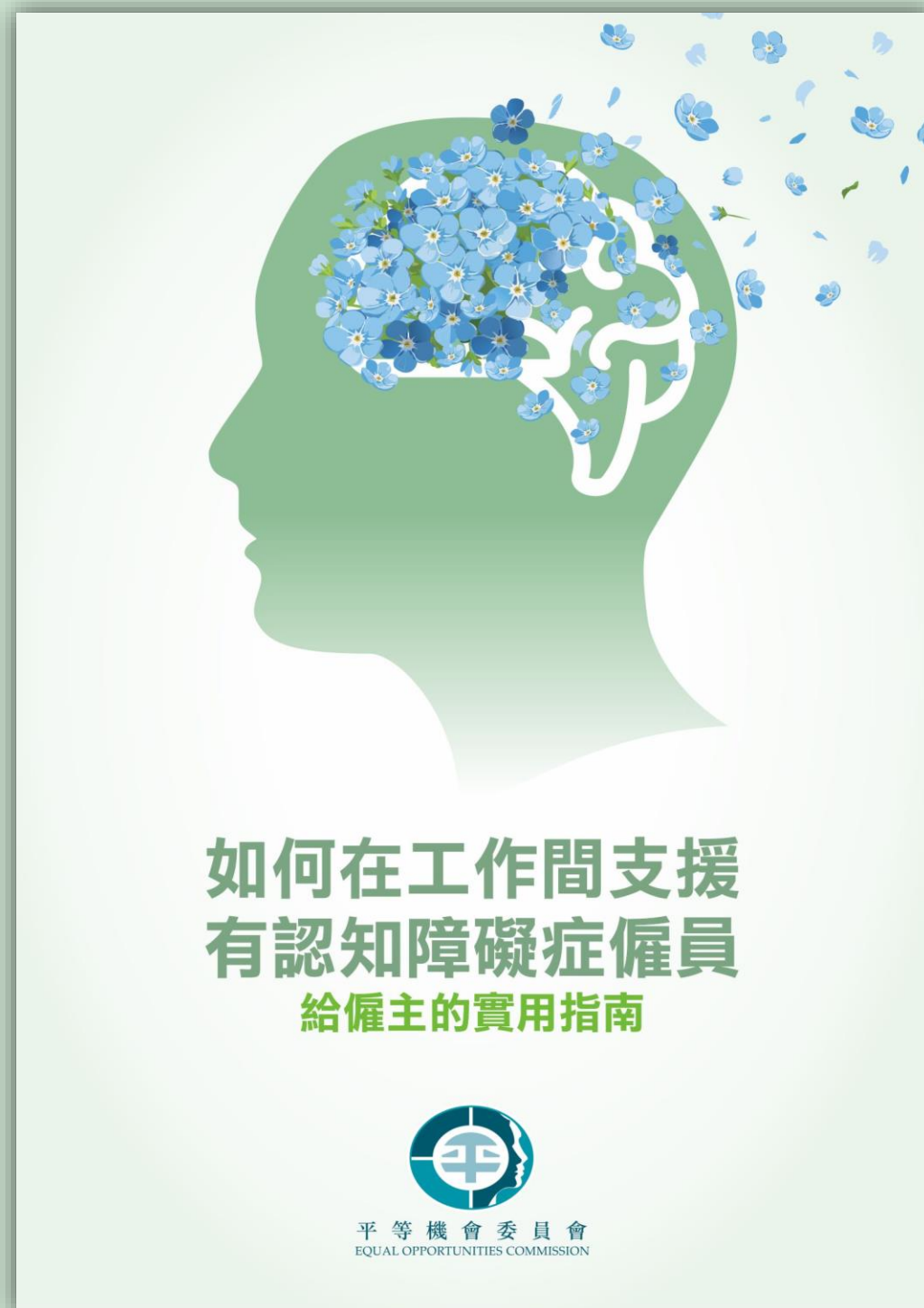




平等機會委員會
EQUAL OPPORTUNITIES COMMISSION

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

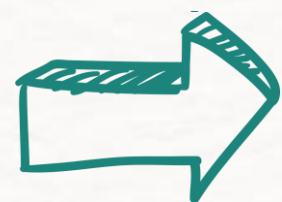
Press Conference
26 September 2024





The situation of dementia globally and in Hong Kong

- In **2020**, there were over **55 million** people living with dementia worldwide
- The World Health Organisation: Up to **9%** of those with dementia experience young-onset dementia (YOD) (onset of symptoms before the age of 65).
- 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**.
- Hong Kong has over **13,000** people who have YOD.
- The youngest onset age found being **38**.



YOD and more older people remain in the workforce, the number of working people with dementia is expected to rise





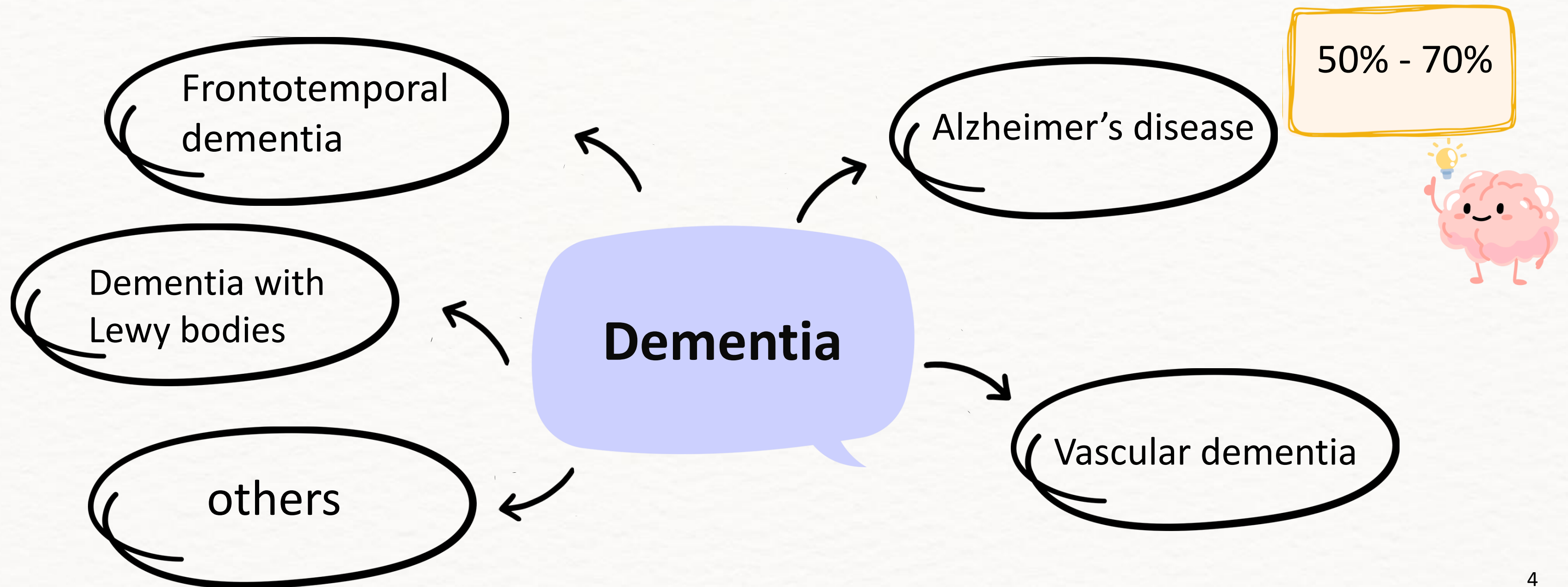
Purpose of this guide

- Promoting a better **understanding** of dementia and the working population with dementia
- Offering **guidance** for employers on **supporting** employees with dementia and those caring for people with dementia.



What is dementia?

- Dementia is an **umbrella** term referring to **various degenerative brain syndromes** affecting one's **memory, thinking, behavior** and **emotions**, etc.





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.



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.



Rights of People with Dementia and Carers

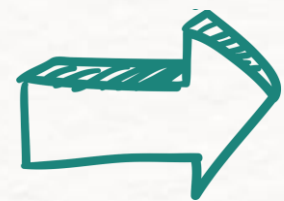
The United Nations Convention on the Rights of Persons with Disabilities (CRPD):

- The rights of persons with disabilities (PWDs) to **fully participate** in society on an **equal basis with others**.
- Article 27 of the CRPD: 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 Disability Discrimination Ordinance (DDO)

- 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, etc.



Dementia is **a form of disability** covered by the DDO.

The DDO prohibits both **direct and indirect discrimination** against PWDs in various public domains, including employment.





Direct discrimination

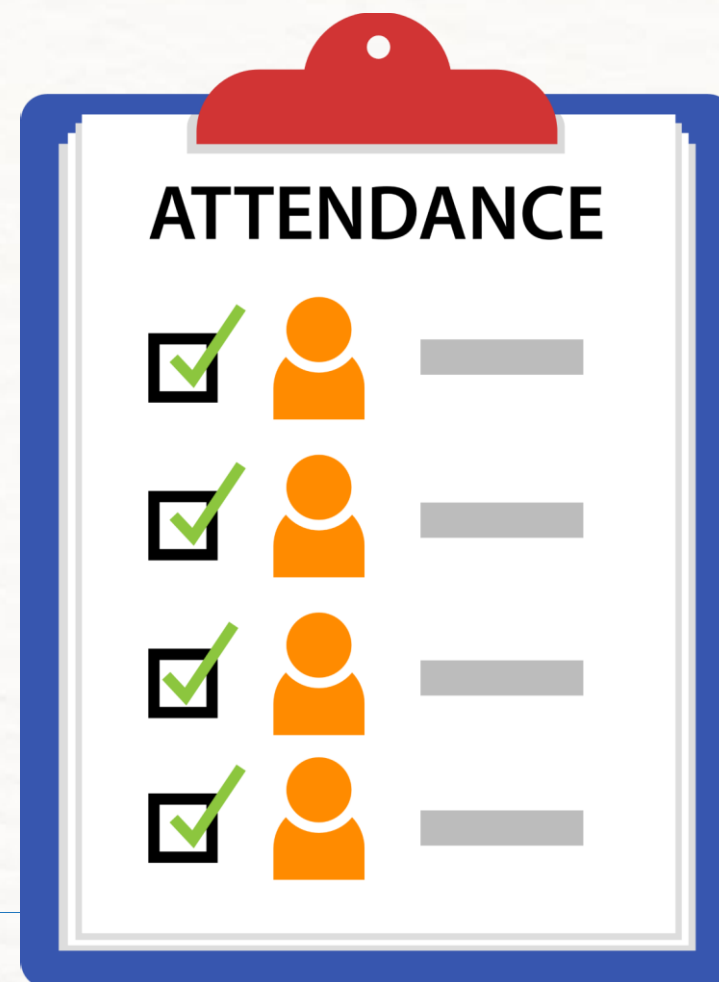
- Direct discrimination occurs when, on the **ground of disability**, a PWD is treated **less favourably than someone without a disability** in similar circumstances.





Indirect discrimination

- 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.



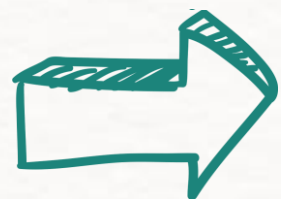
BONUS





The Family Status Discrimination Ordinance (FSDO)

- FSDO: it is unlawful to discriminate against someone on **the ground of his/her family status**.
- “Family status”: 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





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 memory**.

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

- Reality: 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.



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

- Reality: People with dementia can still accomplish many tasks **with guidance**, especially those in the early stages.
- Dementia **manifests differently** in each person.
- Dementia **does not instantly render** someone unable to work.
- The emphasis should be on recognising their existing **strengths and abilities**.

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 for 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** and may eventually develop dementia.





Sharing from people with dementia and carers



Connie

- 52 years old, diagnosed with Alzheimer's disease two years ago
- Worked in a healthcare institution
- Job duties: drug procurement and answering phone calls
- Left her job about a year after diagnosis
- Experienced disorganised thinking, falls, and declining memory
- Struggled to learn new tasks, e.g. ordering drugs by fax and email



Emma

- 66 years old, diagnosed with mild cognitive impairment two years ago
- Over 20 years of experience in the insurance industry, following up on customers' insurance policies
- Forgot to submit a customer's cheque for renewal payment
- Missed the deadline for renewing the customer's policy. Thus, the customer had to purchase a new policy at a higher value



Ruby

Connie's sister
and a working
carer

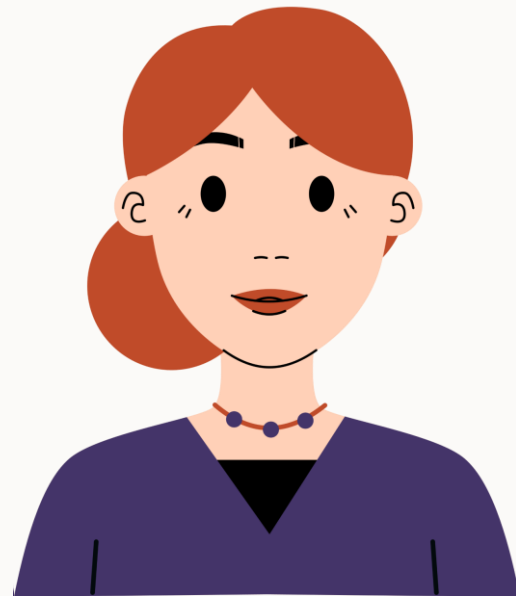


- Feeling puzzled and worried but striving to face the challenges at work.



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.



Emma

...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....

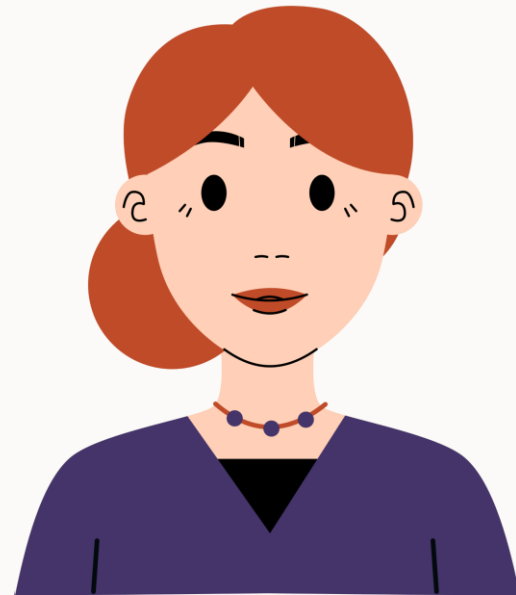


- Not fully aware of their rights or did not want to be a burden to others



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.



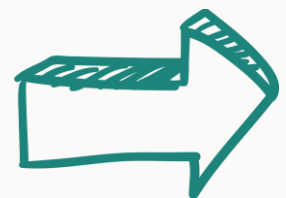
Emma

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



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.



- **Employees with disabilities should communicate their needs to employers when needed.**





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



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....

(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..... (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.....

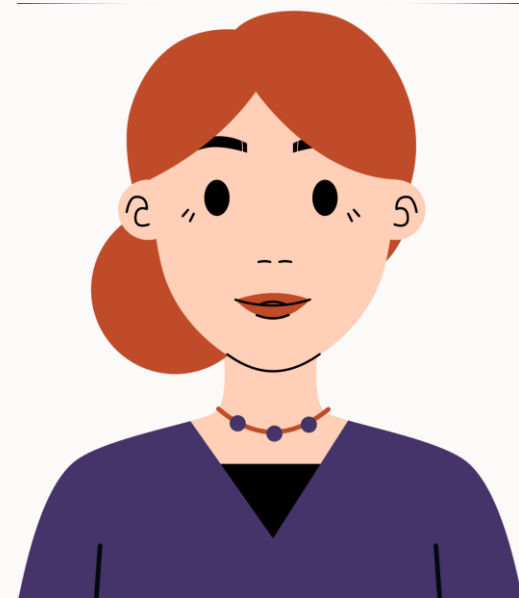


- Looking to the future...



Connie

I feel happy if I can manage (work)...I feel so stressful if I go to work, but it's a waste of time if I don't."



Emma

If there are job opportunities in 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....



- Carer's worries



Ruby

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 home ... What'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....



- *Facing difficulties and grumbles from colleagues when taking leave*



Ruby

(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.



- *Hoping for more flexible work arrangement*



Ruby

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





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Becoming a Dementia-Friendly Workplace





Communication with employees with dementia

 Dos	Don'ts 
Find a suitable place to speak with minimal background noise and distractions.	Interrupt or finish their 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 they can or cannot understand.
Be patient. Give them time to process information and respond.	Call them demented.

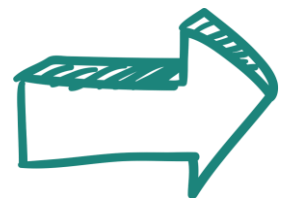




Are employers responsible for providing work accommodation?

- 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, when an employers is **aware of** an employee' s disability that affects his/her ability to carry out the **inherent requirements of a particular job**, the employer should **consider providing reasonable accommodation** unless the accommodation would cause **unjustifiable hardship**.

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.



- **Employers should consult employees with disabilities and seek expert advice for effective accommodations.**





Key points to consider when deciding on work accommodation

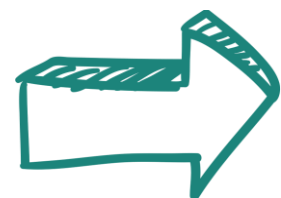
- What **limitations** are the employees facing?
- What **specific job tasks** are problematic due to these limitations?
- How do these limitations affect the employees and their **job performance**?
- What are the **strengths** and **skills** that the employees have developed over time?
- Is there any **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?





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.
- 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 his/her 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**.



Some workplace adjustments are inexpensive and may just involve rearranging existing equipment.





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.



Providing support for working carers for people with dementia

- 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.





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Sharing session

Ms LEE Nga-yee, Maggie

Executive Director,

Hong Kong Alzheimer's Disease Association





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Q & A



Full guide