

如何在工作間
支援

How to
Support Persons
with

腦癇症患者

EPILEPSY @Work



平等機會委員會
EQUAL OPPORTUNITIES COMMISSION

引言 Introduction

殘疾歧視的根源很多時候並非來自殘疾本身，而是我們對殘疾的負面看法或誤解。這些負面看法或誤解，使我們忽略了他們的能力。這本小冊子是平等機會委員會發布的《如何支援殘疾人士》系列內首份刊物，旨在就與腦癇症患者相處的禮儀提供便捷指南，並羅列提供便利措施時的注意事項。

腦癇症並不罕見，任何性別或種族都有可能患上。患者可以在任何年齡發病，但一般是在童年或60歲以後。

全世界約有5,000萬人患有此症。香港有大約六至七萬人有腦癇症這種長期病患。不過，估計七成腦癇症患者可依靠藥物控制發病，正常地生活。然而，腦癇症的負面標籤或會令患者及其照顧者難堪，而且容易遭受欺凌及歧視。

聯合國《殘疾人權利公約》（《公約》）確認殘疾人在與其他人平等的基礎上享有充分參與社會的權利。《公約》第27條訂明，殘疾人享有權利，有機會在開放、具有包容性和對殘疾人不構成障礙的勞動力市場和工作環境中，為謀生自由選擇或接受工作。《公約》第24條呼籲締約國按殘疾人士的個別情況向他們提供合理便利，以實現具包容性的教育環境。《殘疾歧視條例》保障殘疾人士就業和教育等範疇不被歧視。

It is often the stigma attached to or misunderstanding of a disability, rather than the disability itself, that leads to discrimination. Such stigma or misunderstanding overlooks the ability of individuals. This toolkit, the first in the series of "How to Support Persons with Disability" published by the Equal Opportunities Commission (EOC), aims to provide a quick etiquette guide when interacting with people living with epilepsy, and points to note in providing accommodation.

Epilepsy is a common condition in our community and can develop at any age, regardless of gender and race, but generally appear during childhood or in people over 60.

Around 50 million people worldwide have epilepsy. There are around 60,000 to 70,000 individuals living with epilepsy in Hong Kong. Having said that, it is estimated that 70% of people living with epilepsy may have control of seizures with medications and lead a normal life. However, stigma attached to epilepsy may lead to embarrassment, bullying and discrimination against people with epilepsy and their carers in the society.

The UN Convention on the Rights of the Persons with Disabilities (CRPD) recognizes rights of the persons with disabilities (PWDs) to fully participate in society on an equal basis with others. Article 27 of the CRPD stipulates 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. Article 24 of the CPRD calls for reasonable accommodation of the individual's circumstances with a view to realizing the rights to an inclusive education environment for PWDs. The Disability Discrimination Ordinance protects PWDs from discrimination in areas of employment and education, etc.



腦 癇症是一種影響中樞神經系統的疾病。一般而言，如出現兩次或以上腦癇發作，會診斷為患上腦癇症。無論患者有否服用抗腦癇藥物，若過去五年發作了最少一次，即屬病情活躍。

腦癇發作時腦部的電波活動突然失控發放，短暫影響大腦神經運作。腦神經細胞之間的正常聯繫變得混亂，使患者的意識、感覺和身體反應出現短暫的紊亂或不受控。

部份患者的腦癇發作沒有成因，已知的成因包括出生時腦部缺氧而導致的腦部受損、遺傳性腦部疾病、頭部嚴重創傷、腦部感染或腦腫瘤等。

Epilepsy is a neurological condition that affects the central nervous system. Epilepsy is usually diagnosed after a person has had two or more seizures. Active epilepsy is defined as a person with epilepsy who experienced at least one seizure in the previous five years, regardless of antiepileptic drug treatment.

Seizure is a sudden, uncontrolled burst of electrical activity in the brain that temporarily affects how the brain works. The orderly communication between nerve cells becomes mixed-up and a person's thoughts, feelings or movements become momentarily confused or uncontrolled.

Some may not have a clear cause of epilepsy, while others have known causes of epilepsy such as brain damage caused by a lack of oxygen during birth, inherited brain diseases, severe head injury, brain infection or brain tumour, etc.

「我係Tom（化名），除了足球之外，基本上很多球類運動都喜歡，在疫情之前，我會經常打羽毛球、網球和籃球。十幾年前，我已確診腦癇症，亦有腎臟科及肩膊方面的問題，需要長期覆診。最初幾年，雖然有服食抗腦癇藥，但病情未太穩定，曾經試過一年入院三至四次。當時期每次發作前都無先兆，又恰巧在屋企。家人話我知發作時身體會蜷縮，有時就會倒地口吐白沫、咬損舌頭，通常發作維持最多數分鐘左右，就算症狀消失後都要留院觀察一段時間。那段時期，雖然都有一直尋找工作，面試時如果招聘者問我身體有無特殊情況時，我都會如實告知我患有腦癇症，通常招聘者不會再多問，只叫我等消息。最終很多時候都是沒有下文……

努力工作獲得回報 Hard work pays off

Tom（化名 alias）

視我如公司一份子

在2016年左右，醫生建議我換另一款抗腦癇藥後，病情比較受控，每年到腦科覆診大概一年兩次。我經勞工處展能就業科，找到一份貿易公司的文職工作，公司主要做包裝及禮盒的生意，當時我負責一般文書和落單的職務，老闆從未歧視我，視我如公司的一份子，我亦非常努力工作，直至近年市況不佳，公司結束了生意。

尊重彼此有不同的能力

在2020年7月，我再經勞工處展能就業科，找到一份在公營機構做兼職客戶服務助理的工作，並需要整理資料及搬運的工作。每天上班大約8小時，每月工作20至23天左右。試用期後，我獲升為兼職Supervisor，工作時數與之前差不多，會多做一些管理工作。我會繼續努力工作，希望日後若有空缺，可以轉為全職Supervisor。

在我的工作間裏，透過日常接觸，都會感覺到部份同事有個別的特殊情況，例如：有員工是智障人士，或部份同事可能有家庭方面的難題，不過大家都在友好氣氛下工作，尊重彼此有不同才能和特質。我希望更多僱主可以提供這樣多元的工作環境給有不同需要的員工。」

"I am Tom (alias), I enjoy playing many kinds of ball games other than football. Before COVID-19, I usually played badminton, tennis and basketball. More than a decade ago, I was diagnosed with epilepsy. I also have kidney and shoulder conditions that require long-term medical attention. In the first few years, even though I took antiepileptic drugs, my condition was not very steady. I was once admitted to hospitals three to four times a year because of epilepsy. I was lucky to be at home every time I had an episode then. There were no warning signs before an episode, my family told me I would usually curl up on the floor, spit or bite my tongue, and it would last for several minutes. Afterwards, I would be hospitalized for a period of time even the episodes were over. At that period, even though I was actively looking for a job, when interviewers asked me if I have any health conditions, I would disclose I am living with epilepsy, and the interviewers usually would not probe further and ask me to wait for interview results. On many occasions, I did not get any job offers...

Being part of the team

In around 2016, my doctor recommended me to change antiepileptic drug. My condition has since become more or less under control, resulting in having check-ups twice a year only. I found a clerical job in a trading company via the Labour Department's Selective Placement Division (SPD).

The company mainly did business related to packaging and gifts. I was responsible for taking orders and doing clerical duties. My boss never discriminated against me, and saw me as part of the team. I worked very hard at my job and until recent years, the economic situation was not good, resulting in the closure of the business.

Respect persons with different abilities

In July 2020, I found another part-time customer service assistant job at a public organization via SPD. The job also requires data management and manual labour work. I work around eight hours each day, and around 20 to 23 days each month. After the probation, I was promoted to a part-time supervisor role. The working hours are more or less the same as before, but I would be more involved in managerial tasks. I would continue to work hard, and hopefully, I could become a full-time supervisor when there is a vacancy.

In my workplace, I can sense that some colleagues have their own health conditions through daily interactions. For instance, some colleagues have an intellectual impairment and some others have family problems, but everyone works together in a friendly atmosphere, and respect persons with different abilities and characteristics. I hope more employers could provide such diversified work environment for employees with different needs."



「我們公司會聘請及委派合適的人才到不同界別的公司以完成各種工作項目。尋找人才的渠道包括勞工處展能就業科，我們會聘用合適的求職者，安排他們到合適的工作崗位和地點。」

工作能力與一般人無異 His ability is no different from others

Amy (化名 alias)

私人企業項目經理 (負責人事管理, 項目統籌)
Private Enterprise Project Manager
(Human Resources and Project Management)

我初時接觸Tom (化名) 的履歷時，知道他患有腦癇症，名字聽起來好似好嚴重，但我知道其實每個人病情不同，不能一概而論。在進一步了解他的情況後，知道他需要長期服藥，但情況可說穩定。我們在聘請他後，安排他到公營機構做一些前線助理工作，他的工作表現好好，例如可以幫忙解答一些客戶查詢，又可以應付一些勞動性的工作等，他工作地點的上司也滿意他的表現。我們公司在他試用期後升他做Supervisor，亦就他的薪金作出相應調整。

老實說，我們覺得他與一般人無異，至今已在本公司的指派地點工作接近一年，就算他日後真的會有短暫發作，我相信只需要給予他適當的休息，而並不會持續影響他的日常工作。」



“Our company will hire and assign suitable candidates to companies in different sectors for all sorts of work projects. One of the channels through which we find talents is the Labour Department’s Selective Placement Division. We will hire suitable candidates and assign them to appropriate roles and work locations.

When I first got hold of Tom (alias)’s CV, I already knew that he was living with epilepsy. The medical name [in Chinese] seems very severe, but I know that each person’s condition can be different, and it cannot be generalized. After understanding more about his condition, I know that he is on long-term medication, but his condition is quite stable. After we hired him, we arranged him to do frontline assistant work in a public organisation. His work performance is very good, for example, he helps with answering customers’ enquiries, and he can handle some manual work, etc. His supervisor in the assigned work location is pleased with his performance. After Tom’s probation, we promoted him to a supervisory role, and his salary has been adjusted accordingly.

Honestly, we feel that he is no different from any other person, and he has worked in our assigned work location for almost a year. Even if Tom has any seizures in future, we are confident that he only needs to be given appropriate rest to recharge and the impact on his work will not last long after.”

與腦癇症患者相處時的宜忌

應該 Do's 避免 Don'ts

理解患者與其他人一樣，都有個人興趣、目標及喜好的食物，只不過是患有此病而已。病患不代表他們的一切。

People with epilepsy are just like the rest of us. They have their hobbies, goals, and favourite dishes. They just happen to have epilepsy. Focus on the whole person, not just the person's epilepsy.

切勿標籤患者。腦癇是病患，並不能界定一個人。

Don't label someone as 'epileptic'. Epilepsy is a condition and it does not define the person.

認識大部份腦癇症患者的能力和智力無異於其他人。

Recognize most people living with epilepsy can have the same range of abilities and intelligence as those without epilepsy.

切勿假設患者傷殘和不能工作。

Don't assume they are disabled and cannot work.

部分患者因發作的程度嚴重而無法工作，有些則病情輕微，能勝任具挑戰性的工作。

Some have severe seizures and cannot work, while others have mild conditions and are productive in challenging careers.

切勿假設患者不能應付責任重大的工作和承受壓力。

Don't assume they cannot handle jobs of responsibility and stress.

明白腦癇症是身體機能方面的疾病。

Understand epilepsy is a physical condition.

切勿假設腦癇症是精神病。腦癇症的前稱是「癲癇症」，由於患者認為這名稱會令公眾以為該病是精神病，有礙他們融入社會，因此該病於2010年正名為「腦癇症」。

It is NOT a mental condition. In 2010, the Chinese name for epilepsy was renamed from “癲癇症” to “腦癇症” as people living with epilepsy felt that the former Chinese name for epilepsy “癲癇症” would lead the public to think epilepsy was a form of mental condition, and create barriers for social integration.

明白腦癇症不是傳染病。

Understand epilepsy is not contagious.

切勿誤以為與患者相處會令你患上此病。

Don't imagine you can catch epilepsy from interacting with them.

視發作為患者生活一部份。

View seizures as part of the person's daily life.

切勿模仿患者發作。

Don't mimic the seizures.

Do's and Don'ts about interaction with people living with epilepsy:

明白每一位患者症狀各異。明白抗腦癇藥物可有效控制超過七成患者的發作。

視乎腦癇源自大腦哪處，餘下10%至15%患者有機會可透過手術控制病情。

Recognize each person with epilepsy has different manifestations. Understand that with anti-epileptic medications, it's possible to control seizures adequately in more than 70% of people living with epilepsy.

The remaining 10% to 15% are possible candidates for surgery, depending on where the epilepsy originates in the brain.

切勿假設腦癇症不能有效受控。

Don't assume epilepsy cannot be controlled effectively.

表現你對患者的關心。詢問對方有甚麼需要，以及對方發作時可怎樣幫忙。

Show your care. Ask about the person's needs and how you can help if he/she has seizures.

患者最清楚自己的病情，亦有自己的醫生跟進，切勿貿然主動向患者提供醫療意見。

Don't give unsolicited, medical advice as the person knows their condition best and has his/her own doctor.



學習發作的急救須知。

Learn first aid for seizures.

切勿在發作時塞東西進患者的嘴裏或按住患者，制止他的動作。

Don't put anything in the person's mouth or restrain his/her movements during the seizure.

腦癇症患者是否受到《殘疾歧視條例》保障？

是的。根據《殘疾歧視條例》第6條，「殘疾」的定義包括身體的「機能失常、畸形或毀損」，因此腦癇症患者屬於受《殘疾歧視條例》保障的殘疾人士。保障範疇是《殘疾歧視條例》的適用範圍，例如僱傭、教育、貨品及服務的提供等。

僱主或學校如何提供共融和有利的環境，便利腦癇症患者工作和學習？

工作方面的便利

大部分只有輕微程度發作的患者無需工作方面的便利，其他患者則可能視乎個人及工作需要提供不同類型的便利措施。

工作方面的便利令殘疾人士可以求職，執行工作的固有要求（即核心的職能），並與工作場所其他人一樣獲得工作上的平等機會及員工福利。

一般而言，工作方面的便利是指工作的改動或調適，例如：

- 改善工作場所的環境和提供合適輔助設備。例如：確保腦癇症患者在安全的地方工作，以防發作時受傷。
- 更改完成工作的方法。
- 容許殘疾人士按醫生建議就診或放病假。
- 更改工作時間表、安排及做法。例如：安排固定輪班工作，安排工作地點可考慮就近患者的家或支援設施等。



Are people with epilepsy protected under the Disability Discrimination Ordinance?

Yes. The definition of 'disability' under section 6 of the Disability Discrimination Ordinance (DDO) consists of 'malfunction, malformation or disfigurement of the body'. People with epilepsy are considered as having a disability covered under the DDO. They will be protected from discrimination within applicable fields of the DDO, for instance, employment fields, education settings, goods and service provisions, etc.

What can the employer or the school do to provide an inclusive and enabling place for work and study?

Work Accommodation

Most people with milder forms of seizures do not require work accommodation to perform their jobs. For others, the type of accommodation needed will vary according to the individual and the job requires.

Work accommodation enables the person with disability to apply for the job, carry out the inherent requirements of (i.e., essential functions that are clearly central to) the job, and enjoy equal access to opportunities and benefits of the job that are provided to other individuals in the workplace.

In general, a work accommodation is any adjustment or modification to a job, such as:

- Modification of the physical environment of the work premises or provision of suitable assistive equipment. For example, make someone's workspace safer in case he/she has a seizure.
- Change the way in which a job can be done.
- Allow people with disability to take medical appointment or sick leave as recommended by medical professionals.
- Change of work schedule, arrangements and practices. For example, regular shifts rather than variable shifts, or arrange work location nearer to the person's home or support facilities, etc.

誰負責提供工作方面的便利？

Whose Responsibility is Work Accommodation?

個人的層面：

- 殘疾人士是否披露其殘疾和要求僱主提供便利，全屬個人決定。若腦癇症沒有影響患者處理某特定工作的能力，患者可決定不披露病況。雖然很多申請人或僱員選擇披露健康情況，也有很多患者擔心負面看法或可能影響求職或保住工作而選擇不披露。

僱主的層面：

- 僱主發現或知悉僱員因其殘疾需要合理的便利以執行工作的固有要求，繼而考慮提供有關便利，是良好常規措施。
- 然而，即使僱員沒有把其殘疾告知僱主，若僱主可以從殘疾的表徵，或僱員經常或長期放病假，足以推定知悉該僱員有殘疾，僱主便應該了解僱員的殘疾相關需要，研究可以提供哪些工作方面的便利以切合其需要。在這些情況下，除非僱主有不合情理的困難，否則便應提供合理的便利。
- 若僱主實際並不知悉僱員的殘疾，便無義務提供便利。



個人的層面

Individual's perspective

僱主的層面

Employer's perspective

DDO

From the individual's perspective:

- It is the individual's personal decision to disclose his/her disability and request for an accommodation from the employer. If epilepsy does not affect the ability to perform a particular job, the individual may decide not to disclose the condition. Though many applicants or employees may choose to share their medical conditions with others, many others may not because of the perceived stigma or it may impact them getting or retaining a job.

From the employer's perspective:

- It is always a good practice for employers to consider providing reasonable accommodation when they notice or have knowledge that their employee's disability has such a need in order to carry out the inherent requirements of the job.
- However, even if employers are not told about the disability of an employee they may still be regarded as having constructive knowledge of the disability through, e.g. manifestations of a disability, frequent or prolonged sick leave, etc. Employers are advised to communicate and understand the employee's disability-related needs and explore work accommodation measures to address those needs. In that case, they are expected to provide reasonable accommodation unless they have unjustifiable hardship in doing so.
- Employers are not responsible for providing accommodation where the employer has no actual knowledge about an employee's disability.

決定提供哪些工作便利時的考慮因素

Points to consider when deciding what work accommodation is needed

由於腦癇症患者的症狀不一，因此須評估個別患者的情況。

一旦患者要求提供便利，僱員及僱主應考慮以下各點：

As people experience epilepsy in many different ways, it is very important to assess each person's condition on a case-by-case basis. Once an accommodation request is made, the employer and employee should consider the following:

工作的主要職責是甚麼？

What are the essential functions of the job?

要求合理便利的人有何身體機能限制？

What are the functional limitations of the person asking for accommodation?

哪些具體工作會受有關身體機能限制影響？

What specific job tasks are affected by those functional limitations?

需要哪些設備或調適以執行工作？

What types of equipment or adjustments are needed to do the job?

是否有工作程序會影響患者執行工作的能力？

Are there work procedures that affect a person's ability to do the job?

提供工作的主要職能清單或有助醫生給予適當意見。Providing a list of the essential functions of the job may assist medical practitioners in providing appropriate input.

患者的普通科醫生或腦科醫生通常可以在提供便利的過程中給予醫學評估。患者可要求醫生提供有關工作便利措施的醫生證明書，協助僱主作出安排。

The employee's doctor or neurologist can usually offer medical assessment in the accommodation process. The employee can ask their doctor to prepare a medical note on work accommodation to assist the employer in arranging work accommodation.

便利措施可以很簡單，例如準備枕頭或軟墊覆蓋地板，給予患者休息時間，或讓他們發作後放假。Accommodation can be simple, such as having pillows ready or pads to cover the floor for individuals with epilepsy, giving breaks to them or allowing them to take time off after a seizure.

《殘疾歧視條例》的適用條文

- 根據《殘疾歧視條例》第6、11及12條，若僱主知悉申請人或僱員的殘疾，而他們要求提供便利，僱主應為他們提供合理的便利，以協助他們執行工作的固有要求，但如這樣做會為僱主造成不合理困難，則屬例外。
- 根據《殘疾歧視條例》第4條，在決定甚麼構成不合理困難時，須考慮有關個案的所有情況，包括——

a) 向殘疾人士提供任何便利的合理程度；

b) 可能帶給任何有關人士的利益或令其蒙受的損害的性質；

c) 有關人士的殘疾的影響；及

d) 聲稱有不合理困難的人的財政情況及其所須付出的估計開支(包括經常性開支)款額。

- 《殘疾歧視條例》沒有要求僱主更改某職位的工作性質或工作的固有要求，從而配合個別殘疾員工的需要。便利的形式可以是提供服務或設施方面的協助。

- 若申請人或僱員基於其殘疾而未能執行某特定工作的固有要求，僱主或未必須提供合理的便利。然而，僱主宜在作出此決定前索取醫療資訊及進行評估。



What the DDO says:

- Under sections 6, 11 and 12 of the DDO, if the employer has knowledge of the disability of an applicant or employee, and the applicant or employee requests for accommodation, the employer is expected to provide reasonable accommodation to the applicant or employee with disability, in order to assist him/her to perform the inherent requirements of the job. The employer should consider providing accommodation unless by doing so, it would impose an unjustifiable hardship to the employer.

- Under section 4 of the DDO, in determining what constitutes unjustifiable hardship, all relevant circumstances of the particular case are to be taken into account including –

a) the reasonableness of any accommodation to be made available to a person with disability;

b) the nature of the benefit or detriment likely to accrue or be suffered by any persons concerned;

c) the effect of the disability of a person concerned; and

d) the financial circumstances of and the estimated amount of expenditure (including recurrent expenditure) required to be made by the person claiming unjustifiable hardship.

- The law does not impose an obligation on an employer to alter the nature of the particular employment or its inherent requirements so as to accommodate the employee with a disability. Accommodation can be done by provision of assistance in the form of services or facilities to help the employee to do the job.
- If the disability of the applicant or employee renders him or her unable to perform the inherent requirements of the particular job, the employer may not need to consider accommodation. However, it is strongly advisable that medical information and assessment is obtained before reaching this conclusion.

教育方面的調適

普遍而言，教育方面的調適是為殘疾學生提供平等機會而採取的任何措施或行動，例如提供輔助器材、設施或服務照顧個別需要。為了確定患者所需的調適安排，醫療專家、教育心理學家或社工可能需要作出詳細的評估，而每宗個案都應按其本身的情況作出考慮。

決定提供哪些教育方面的調適時的考慮因素

調適安排的類型和程度可能取決於個別學生的具體需要和其他相關情況。在確定需要作出何種調適時，應考慮以下因素及情況：

所提供的調適是合理地達到目的，即合理地照顧到有關學生的教育及訓練需要；

調適的重點在於提高學生的獨立能力；

調適對學生造成最少的打擾和干預；

調適對其他牽涉人士的影響；以及

提供或維持調適的財政支出。



School Accommodation

In general, a school accommodation is any measures or actions taken in order to provide equal opportunities for students with disabilities, such as the provision of aids, facilities or services to meet his or her individuals. A detailed assessment, sometimes from various parties such as medical professionals, educational psychologists or social workers, may be required in order to determine what accommodations are necessary and each case needs to be considered with regard to its own circumstances.

Points to consider when deciding what school accommodation is needed

The type and extent of accommodation may vary depending on the individual and specific requirements of the student and other relevant circumstances. In determining what accommodations are to be made, the following factors and circumstances should be considered:

The accommodations are reasonable for the purpose; that is, they reasonably fulfill the educational and training needs of the student;

The accommodations are focused on enhanced student independence;

The accommodations are the least disruptive and intrusive for the student;

The impact of the accommodations on anyone else affected; and

The cost of providing or continuing the accommodations.

「我今年在香港科技大學就讀BBA三年班。我讀大學一年班（大一）時住在宿舍。在2019年年底一個晚上的半夜時分，室友告知我，在我睡覺時第一次發作了。當我清醒時，大學已召喚救護車，在留院後確診腦癇症，需要服食抗腦癇藥。在接近完成大一課程時，病情雖然不影響學業，但藥物有時令我感到疲倦，幸好病情受控，加上疫情期間大學安排在家以Zoom形式上課，多了休息時間。

我的病患不是我的全部 My health condition does not define me

Jane (化名 alias)
科大BBA三年班
Year 3, BBA, HKUST

我在2020年暑假開始找實習工作，又經配對機構幫忙找實習機會。第一份實習工作的面試經過是在配對機構偶然發生。當時有一位老闆到配對機構想招聘實習生，我剛巧在配對機構提交一些資料給機構職員，職員向那位老闆簡述了我的CV和情況，老闆便說想見一見我。整過面試過程仿如一般傾談。他說公司是初創企業，問我是否有興趣做Marketing的實習工作。我感到機會難得，慶幸在面試後順利獲聘，在該公司實習約三個月，累積了Marketing方面的實戰經驗。

我希望其他僱主都可以透過親身接觸，明白到一個人的病患並不代表那個人的全部，並提供機會給與自己不一樣的員工。這間公司給了我第一次的工作經驗，有助於我今年尋找更多的實習機會，現正等待兩份不同類型的實習工作的面試結果，一份是Back Office的Operations，另一份在大學協助做研究的工作。無論那一份工作聘用我，我都會努力工作，從中更了解自己的專長，計劃在畢業後的路向，期盼在不同機構所累積的工作經驗可以幫到我畢業後找到一份好工。」

"I am studying Year Three BBA at The Hong Kong University of Science and Technology. I lived in student hall in Year One. During the middle of a night towards the end of 2019, my roommate told me that I had a seizure during my sleep and it was my first episode. When I was awake, the University had already called an ambulance, and I was diagnosed with epilepsy after hospitalization and needed to take antiepileptic medication. Towards the end of Year One, even though the drugs made me drowsy sometimes, it does not affect my studies and I am glad that the condition was under control. Owing to the University's arrangement of online learning via Zoom during COVID-19, I had more time to rest as well.



I started looking for summer internship in 2020. My interview for my first internship happened while I was in the job-matching agency. A company boss was there looking for an intern in the job-matching agency, I happened to be there to submit my CV and information to the agency staff. The staff briefed my CV and my condition to the boss, and he wanted to meet me. The whole interview process was more like a chat. He said that his company was a start-up, and asked if I was interested in marketing. I felt that the opportunity was precious, and was grateful that I was hired after the interview. My internship lasted for three months and I accumulated hands-on experience in marketing.

I hope that other employers can make use of face-to-face contact in order to understand that anyone who has a medical condition does not define that person, and provide opportunities to people who are different from them. The above company has given me my first work experience, and such experience helped me to find more internship opportunities this year. I am now waiting for the interview results of two different kinds of internships. One is more back office work focusing on Operations, while the other is research work. No matter which company hires me, I will try my best to excel, gain better understanding of my strengths, and plan for my career after graduation. I hope that various experiences gained from different companies could prepare me to get a good job after graduation."

在工作或學校環境為腦癇症患者提供便利或調適的例子

- 安排定時工作或學習時間，因為睡眠模式或會影響發作。

- 由於發作前腦部狀態短暫出現變化，因此可在發作後給予較長休息時間。

- 重新編排測驗或工作時間，協助患者調適，得以盡展才能。

- 與患者溝通，了解提供以下物品是否有用：患者跌倒時可以給予保護的膠墊、書桌或櫃台的護角墊、扶手較高的椅子，或協助記憶的書面指示。

- 患者在工作地點或學校發作時的任何個別具體要求，例如如何教導同學或同事認識腦癇症、如何或何時致電999、是否需取得緊急聯絡資料、需要認知哪些視聽預示症狀等。

- 更換不時閃動的光管，因為可能會引致對光敏感的患者發作，但不是所有腦癇症患者均受影響。

- 評估及監察便利措施的成效。保持開放態度，儘管以往的某些便利措施有效，但可能因患者由中學升讀大專院校等情況或環境有變而未必再有效用。



Some examples of accommodation for people living with epilepsy in work or educational settings

- Arrange regular work or study schedules because sleep patterns can play a role on seizure manifestation.

- Give extended breaks following any seizure activity because seizure activity is followed by a period where a temporary change in the state of mind is expected.

- Reschedule tests or tasks to help them reset and show their full potential and mastery of the subject matter.

- Communicate with them about whether it would be useful to provide: rubber mat to cushion a fall, pad edges of desks or counters, chairs with deep arm rests, or written notes of instructions as memory aids.

- Any specific requests from the people with epilepsy for their personal plan of action should a seizure occur at work or at school such as, how best to educate peers or colleagues about epilepsy, how or when to call 999, emergency contact information, visual or audible warning signs, etc.

- Replacement of fluorescent lighting that blink or flicker periodically as this may cause seizures in photosensitive individuals, but not all people with epilepsy would be affected.

- Evaluate and monitor effectiveness of accommodation. Be open-minded that even if specific accommodations worked for an individual previously, that does not mean they will work now due to changing condition or environment, e.g. transition from secondary schools to tertiary institutions.

要求提供便利或調適時應提交甚麼資料？

What should be included in the request for accommodation?

- 合適醫護人員或職業健康診所的證明書(如醫生證明書)，以證明：
 - i. 患者的殘疾資料或殘疾性質；
 - ii. 所需便利措施的類型；以及
 - iii. 需要便利措施的大概持續時間(如適用)。
- 提供便利措施的要求宜以書面提交，這樣有助避免日後爭議。在醫生證明書中註明需要便利措施亦屬普遍做法。
- Documentation from an appropriate medical professional (e.g., doctor's note) or occupational health services that verifies:
 - i. the disability or nature of medical condition of the individual;
 - ii. the type of accommodation needed; and
 - iii. approximate duration of accommodation (if applicable).
- It is also preferable that the request for accommodation to be provided in writing. This may help avoid disputes in the future. It is also common that accommodation needs are stated in medical certificates.

僱主或學校可否要求腦癇症患者提供醫療/殘疾資料？

Can the employer or school request information about an individual's epilepsy?

- 根據《殘疾歧視條例》第42條，若為了作出歧視行為而要求殘疾人士提供資料，例如要求提供完整醫療報告，而有關資料超出僱主或學校的合理需要，該要求便屬於違法。
- 只要目的是必須和合理，僱主或學校可要求提供所需醫療資料，以決定：
 - i. 患者的殘疾會否令他/她不能執行工作的固有要求，或
 - ii. 患者是否需要服務及設施以執行工作的固有要求。
- 若患者的病況或對便利措施的需要並不明顯，僱主或學校可要求適當的專業醫護人員提供證明書，證明患者有權需要便利措施。
- Under section 42 of DDO, it is unlawful to request information for the purpose of discriminating the person with disability, e.g., a request for a complete release of medical records exceeds the employer or school's legitimate need for information.
- The employer or school may request medical information as long as the intended purpose is necessary and justifiable to determine if:
 - i. a person's disability would prevent him/her from carrying out the essential functions of a particular job; or
 - ii. a person would require services and facilities in order to perform the essential functions of the job.
- If an individual's condition or need for an accommodation is not obvious, the employer or school may request documentation from an appropriate medical professional to demonstrate the individual's right to accommodation.

發作的病徵

Examples of manifestations of seizures

- 感官異常、頭暈、目光呆滯、眨眼、舔唇、動作重複、哭泣或大笑和尖叫。
- 突然跌倒、手腳痙攣、身體僵硬、搖動、失禁、咬舌及失去知覺。
- Alterations to sense(s), dizziness, staring blankly, blinking, lip smacking, performing repetitive movements, crying or laughing and screaming.
- Falling down suddenly, quick twitching of the arms and legs, stiffening of the body, shaking, loss of bladder or bowel control, biting of the tongue and loss of consciousness.

急救小貼士

Seizure first aid

保護患者避免受傷。
移開附近物件。
Protect them from injury.
Remove harmful objects nearby.

若患者倒在地上，
用東西墊着頭部，
並鬆解頸部的緊束衣物。
Cushion their head if they fall down and loosen tight clothing around their neck.

告訴患者你會陪伴他們，直至完全復原，或若召喚了救護車，直至有醫護人員到達，使患者放心。
Reassure them you will stay with them until the recovery is complete or until a paramedic arrives if an ambulance has been called.

待患者自然停止抽搐後，使其下巴輕微向上以協助呼吸，輕力把患者置於復原臥式的姿勢。
If there is jerking, after it ends naturally, aid breathing by tilting their chin upwards and gently placing them in recovery position.

記錄發作持續時間。
Time the seizure.

若患者有知覺，有耐性地輕聲與他們說話，詢問他們是否有任何不妥。
When they are alert, calmly and patiently talk to them and ask if they are okay.

陪伴患者，直至他們完全復原。
Stay with them until they are fully recovered.

向患者解釋任何他們記不起的事情。
Explain anything they have missed.



若有以下情況，請召喚救護車。 Call for an ambulance if ...

- 患者是首次發作，或者你不清楚是否首次發作。
- 你不清楚他們是否需接受緊急治療。
- 他們在發作時受傷。
- 發作 / 抽搐時間超過五分鐘。
- 反覆發作，期間沒有恢復知覺。
- 有關人士是孕婦。
- 你沒有信心處理事件或有任何疑慮。
- It is their first seizure, or you are not sure.
- You have doubts whether they need urgent medical attention.
- They are injured during the seizure.
- The seizure/jerking continues for more than five minutes.
- Repeated seizures without regaining consciousness.
- The person is pregnant.
- You are uncomfortable dealing with the situation or have any doubts.

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