Information for educators about cystic fibrosis

This information has been produced for Australian education providers, including tertiary and TAFE organisations, lecturers, tutors and other educators, who have a student with cystic fibrosis (CF). It provides an overview of what CF is, how it impacts daily life and information about ongoing management. Our aim is to inform educators about CF, and provide ways for individuals and organisations to support students to achieve their education goals.

WHAT IS CF?

CF is a progressive genetic condition that causes persistent lung and digestive issues. Respiratory infections can result due to mucus clogging the airways and trapping germs (bacteria and viruses), leading to complications, such as scarring of the lungs or lung failure.

CF is the most common genetic condition in Australia, impacting approximately 3,500 people. Due to significant advances in clinical care, treatments and medication, those living with CF can now expect to live a relatively normal life.

While people with CF may look outwardly healthy, they are living with a chronic condition that affects their body in many ways. It is a complex condition that impacts multiple organs in the body, primarily the lungs and digestive systems. Due to a variety of factors, the health and severity of symptoms vary greatly in people with CF. Everyone's journey is different.

People with CF predominately manage their condition at home and sometimes may be required to engage in treatment during the day. People with CF regularly liaise with a specialist clinical team.

STUDYING AND CF

People with CF are fully capable of independently managing their health. Due to the health demands of living with CF, efficiency, time management, self-sufficiency, hygiene and determination become innate.

Because there is a high degree of variation in the severity of symptoms that people with CF experience, some may have minimal health concerns and others can be chronically ill.

Most people with CF have a persistent cough that increases in frequency when they have an infection. It is important to note that this daily, persistent cough is not contagious. Due to the demand on the body to breathe and function at the same capacity as someone without CF, people with CF can quickly become tired and lethargic, particularly when they are unwell.

As the educator of someone with CF, information you may find useful includes:

- Understand that lung infections feel like having constant bronchitis. People can feel okay or really unwell.
- Stomach issues are common. Frequent short bathroom breaks may be necessary.
- Coughing is normal and helps maintain lung health. It isn't contagious or harmful to others.
- People with CF are at greater risk of illness from bacterial and viral infections. This risk is increased when they are in close proximity or in enclosed spaces with others who have a respiratory illness.
- Considerable time is spent doing daily treatments, exercise and attending appointments, which reduces the amount of time available for study.
- Each person with CF has a different experience. Avoid stereotyping the condition.

If you have a student with CF:

- Ensure a private space is available in case the person with CF needs to take nebulised medications.
- Promote the use of hand sanitiser to all students to help reduce virus and bacterial transfer.
- If required, provide space in a communal refrigerator to keep necessary medications cool.

WHAT ARE CF CLINICS?

Almost all people with CF have a clinical team that supports their health. Weekly outpatient respiratory clinics are held throughout the year, which people with CF may attend about every three months, at major hospitals and regional health centres. These appointments may change in frequency, depending on the person's circumstances.

Clinic team members include respiratory clinicians, psychologists, dieticians, social workers and physiotherapists. Due to the complexity of CF, the person must attend clinics to ensure their baseline health is monitored and maintained. At clinic appointments, indications of reduced lung health or deterioration are addressed.

You can support your student by:

- Understanding that clinics are long, intense days, where people have little control over time and delays. Typically, they are several hours long at a minimum.
- Being flexible with assignment deadlines when required, to accommodate and support clinic attendance. By skipping clinics, a person's health can decline, ultimately impacting their home and work life.

The CF Strong project is funded by the Australian Government.

WHAT ARE HOSPITAL ADMISSIONS FOR?

Hospital admissions are common for people with CF, and can at times be planned to help maintain baseline health. They are required as a preventative measure to preserve baseline health, or when an infection is particularly difficult to control or clear.

Admissions usually involve targeted antibiotics, steroids, nutritional care and intense physiotherapy. Some people require the full treatment as a hospital inpatient, and others are eligible for Hospital in the Home (HITH) after a shorter stay of three to five days. The frequency of admissions can range from once every few years to every few months, depending on the severity of the person's illness.

Admissions are important to recuperate energy, maintain weight and return to baseline health.

Depending on the health of the person and the complexity of their treatment, they may be able to work on course material or assignments during this time, or they may be asked by their treating team to rest during and for a period of time after their admission.

If you have a student with CF who is admitted to hospital:

- Understand that CF is unpredictable. Some infections are serious and require immediate treatment. If admissions to hospital are recommended, people have little choice about this.
- Discuss any upcoming assessment tasks, especially those where the student with CF may be part of a group project, and offer possible solutions, such as an extension or additional support.
- Allow for alternative strategies for meeting mandatory attendance requirements.

Responsibilities of education providers

- Advise if your organisation has a medical clinic that is bulk billed for students. Help navigate services that your organisation offers for people with chronic medical conditions.
- Cross-infection is a major issue to people with CF. If there is another individual at your organisation with CF, it is important you make them both aware, so they don't transfer harmful bacteria to each other.
- Understand that CF is a fluctuating condition. There will be times of both good and ill health.
- Communication is important. Health can decline with stress, so encourage open communication to reduce pressure.

If you would like more information on CF or ways to support your student, contact your state CF organisation and ask for the services team or social worker.

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